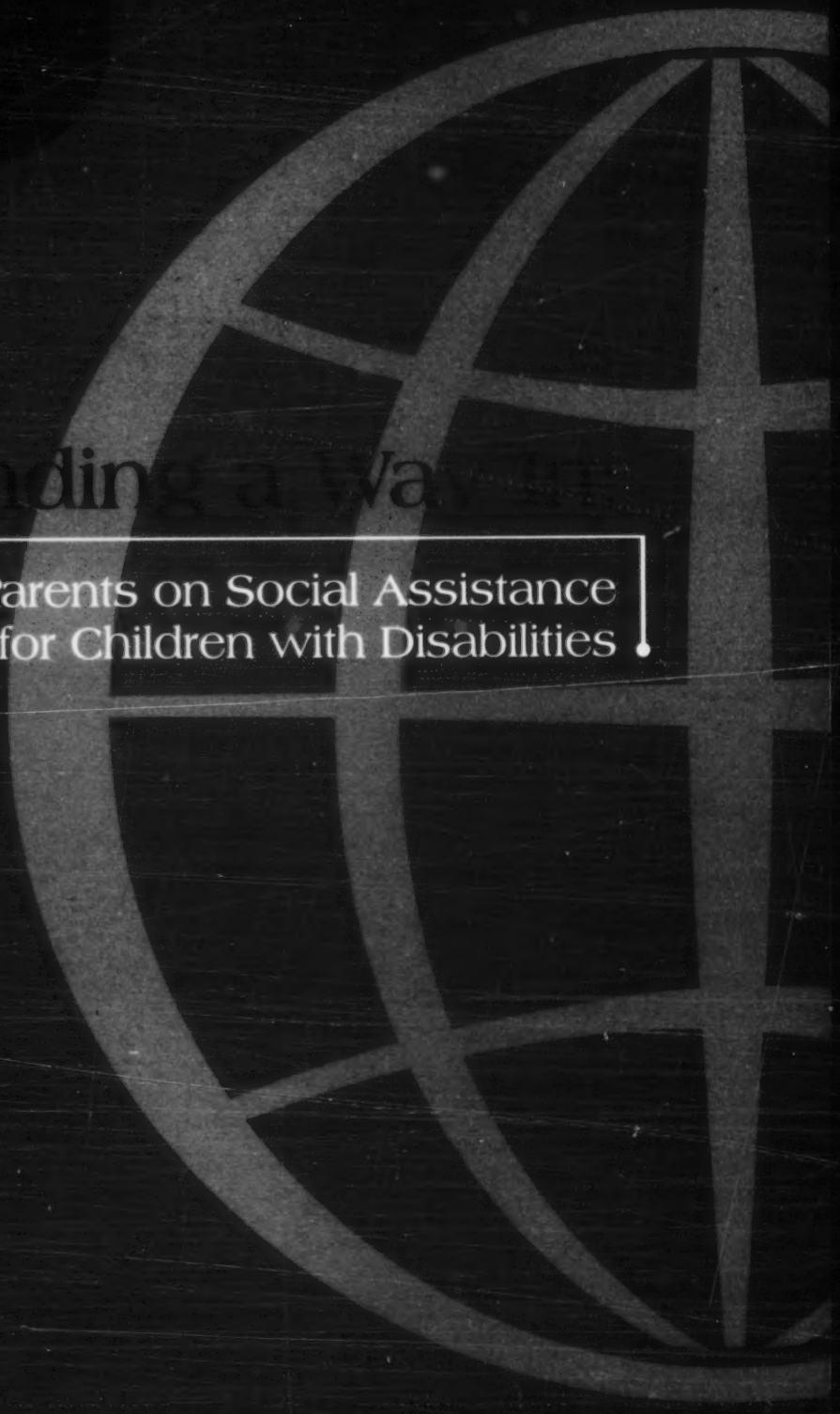
Children and

Finding a Way In

Parents on Social Assistance
Caring for Children with Disabilities



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FINDING A WAY IN:

PARENTS ON SOCIAL ASSISTANCE CARING FOR CHILDREN WITH DISABILITIES

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About

L'Institut ROEHER *Institute*

Canada's National Institute for the
Study of Public Policy Affecting
Persons with Intellectual
and Other Disabilities

L'INSTITUT ROEHER INSTITUTE IS CANADA'S POLICY RESEARCH ORGANIZATION promoting the equality, participation and self-determination of people with intellectual and other disabilities, by examining the causes of marginalization and by providing research, information and social development opportunities.

To fulfill this mandate, The Institute is engaged in many activities: research and public policy analysis; publishing; information gathering and dissemination; and training, education and leadership development.

The Institute acts as a centre for the development and exchange of ideas, all of which are founded on a new way of looking at disability in the context of a strong civil society. It critically examines issues related to the well-being and human rights of persons with disabilities. Based on its examination of these issues, The Institute raises awareness about the barriers that affect people's full participation in society and that prevent them from exercising their rights. The Institute also presents policy and program alternatives.

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FOREWORD

Children are a gift and are worth all the sacrifices that parents — and communities — make to ensure that they grow healthy and strong, happy and confident. However, parents of children who have a disability cannot always count on receiving the support of their community so that they may enjoy this gift of life in their midst.

Parents of children with disabilities know the world of sacrifices such as job offers and advancements that sometimes do not arrive because parents must shift attention away from their career on account of their child's health or other issues relating to disability.

Then there is the chance for a better job in a new city that has to be passed up because parents can not count on knowledgeable, available and affordable support for their child in the new community. The hours sometimes spent at doctors' and specialists' offices, which eat into the precious little time left for laughter and outings with family members and friends.

There remains the sometimes strange and lonely world apart from other people in the community, who just cannot relate to what it means to be the parent of one or more children who have a disability. Sometimes, in addition to these stresses and strains, there is life after the spouse has left because usually he does not know how to deal with the pressures inherent in having a child with a disability. So, now, on top of everything else, one parent is left to deal with all the new insecurities and anxieties that come with being a lone parent of a child who has a disability.

Many parents find themselves in an untenable situation. On the one hand, like any other parent they want the best for their children. So they want to make contributions to the economy and to the social fabric of the community that will be valued by others. Indeed, many have made such contributions for years in almost all imaginable careers and walks of life. After all, like other parents they need an income; caring for children costs money and doing well for your children is very difficult when you are poor.

On the other hand, many of the conditions are simply not in place that would enable parents to continue meeting their financial goals while at the same time providing the nature and level of care needed by their child. The child may have complex or chronic medical needs and may require more or less constant attention. There may be little other support available aside from that provided by the mother, father or siblings. The child's condition may not be well understood even by the most knowledgeable professional, so issues of intervention, treatment and support are in a constant state of flux and development, necessitating the parents' close scrutiny. Attending to the child's needs may simply not be "optional" in any sense: her physical life may depend on nothing less than "quality time" all or much of the time from her mother and father.

Facing such difficult challenges of integrating economic and other family responsibilities, many parents find themselves being edged out beyond the picture frame. Some find themselves in a very different place than what it's like inside the picture. They find themselves moved from the normalcy of home, community,

job, friends and acquaintances, to the loss of virtually everything they had previously known. It's as if there were no place for them or their children in the picture; it's as if any trace of their presence has been completely erased. In the often desperate and all too silent grip of the "safety net," the parents' most pressing priority is, with few resources, to do well for their children, and maybe, one day, find a way back in.

Finding a Way In is about what life is like for parents who have been moved beyond the edge of the picture frame into the world of social assistance. Many of the stories are about mothers, but not exclusively. The parents are struggling like other poor parents to make ends meet, while upholding with strength and without compromise the value of their children, who need to be cherished as children above all, and to be known only secondarily as having disabilities.

The report draws from in-depth interviews with parents in three provinces (British Columbia, Alberta and Ontario) who find themselves in the welfare system because the supports that they and their children need for getting back into the picture are not in place, are not affordable, or are just closed to them. These parents talk about their children, their situations, and the supports that are needed to realize their dreams for the future. To provide a context, the research scans statistical sources and the research literature, which are curiously silent about the situation of parents and families of children with disabilities. After all, such parents are over-represented among those who are poor and reliant on public support for basic needs. The report also provides a snapshot of policy and legal measures in place that perhaps could help parents and children to find a way in, one day, but which are not effectively opening the door today.

More positively, the policy directions laid out in this report, if adopted, would, we believe, go a long way towards helping many parents of children with disabilities find a way in, not only to employment, but to patterns of life that are more sustainable, to better child and family health, to social integration, and to other essential conditions without which human dignity and well-being are seriously compromised.

I would like to thank the Employability and Social Partnerships branch of Human Resources Development Canada, who provided the funding for this research, and for their patience and humane approach to a research process that at times was considerably more involved and time consuming than we had initially anticipated. In terms of The Institute's research team, particular thanks are due to Michael Bach for his role in coordinating and overseeing the research. Catherine Stewart, Karen Oster and Mary Bunch conducted the interviews. Catherine Stewart conducted other background research and, in collaboration with the research team, drafted the written text of the body of the report. Orville Endicott researched and wrote the sections on legislative provisions and case law, which can be found in the Appendix. Thanks are also due to Drs. Sharon Hope Irwin, Ernie Lightman, Aileen Wight-Felske and Anne George for reviewing and providing helpful comments on drafts of the report.

More importantly, I would like to thank the families who shared their time and their stories with us, for their openness and generosity, for their courage and strength of spirit, and for the lessons they teach us about what it means to care for children. We sincerely hope that this report will take its place alongside other works that not only tell what is and point to what could be, but which play a part in helping to make what could be a reality. The children and families we have had the privilege to meet along the way deserve nothing less.

Cameron Crawford
President

I. INTRODUCTION

Over the past two decades, broad social and economic trends have given rise to important changes in the structure of the Canadian Family. In the wake of the changing nature of the Canadian family, issues related to childcare have taken on a new urgency. The growing number of mothers with preschoolers who are working outside their home has accentuated the need for more widely available and affordable childcare arrangements. For parents who have children with disabilities, the need for inclusive childcare arrangements that are respectful of children's differences, strengths and needs has never been greater.

Childcare assists working parents by providing care for their children while they work, attend school or training programs, and it enables women to achieve greater social and economic independence. Children can benefit through the opportunity it provides for socialization and healthy development. It can provide a support system for families, which is especially important to those for whom having a child with a disability complicates caring.

Despite the improvement in childcare arrangements across the country in recent decades, parents continue to encounter many obstacles of access regardless of where they live. Such issues include the lack of a clear policy mandate to ensure the availability of childcare for all children and families in need, competing claims for public resources, under-funding of childcare and childcare workers, the lack of funded spaces, long waiting lists, discretionary admission criteria and high costs.

All such factors can make it particularly difficult for children with disabilities to gain access to the "system" of childcare in this country. Add to this the often complex and unexpected demands facing families of children with disabilities, insecure funding for disability programming, funding cuts, lack of training and professional knowledge about disability in the childcare sector, not to mention the regular demands of juggling family life and jobs where employers may not be particularly knowledgeable or sympathetic to the pressures on employees who have one or more children with a disability.

Little wonder, then, that some families buckle under the weight of such challenges. Previous research undertaken by The Roeher Institute has explored the situation of parents seeking to remain in the paid labour force while continuing to care for their children with disabilities, and has documented measures needed in workplaces and in the childcare system to make this goal achievable. Nevertheless, the goal has not been achieved.

As a result, many parents — usually mothers — find themselves edged out of the labour market and unable to secure access to the child and family supports that would enable them to find a way back into employment. Many find themselves on one of the country's income support programs, notably Employment Insurance or social assistance (i.e., welfare).

This research explores the scope and nature of issues faced by families of children with disabilities who are on social assistance. It pays particular attention to the barriers to labour market participation that these families encounter. It also lays out policy

directions that we believe will enhance inclusive childcare and a range of other supports needed to enable family members caring for children with disabilities to make the transition from social assistance to work.

The research draws from a literature review, an analysis of the policy framework and of legislative provisions, and from in-depth interviews with parents on social assistance who have children with disabilities.

Chapter II of the report provides a summary of the methodology that was used. Chapters III and IV set the context by summarizing key demographic information, and by providing an overview of what the literature tells us about issues of making the transition from social assistance to employment while caring for children with disabilities. Chapter V explores the policy and legislative framework, federally and in three provinces: British Columbia, Alberta and Ontario. Chapter VI provides a profile and the experiences of parents on social assistance who are caring for children with disabilities. Chapter VII provides some recommendations for actions that are needed to address the situation faced by such families and by society more generally in its efforts to integrate economically the working-age population. The Conclusion brings the discussion to a close. The Appendices include references, an overview of selected statutory and case law provisions related to childcare in Canada, and the interview guides that were used in the interviews with families.

II. METHODOLOGY

The Roeher Institute undertook this research project with objectives to:

- Determine the scope and nature of issues faced by families who have children with disabilities who are on social assistance, especially with respect to barriers to labour force participation.
- Identify the most effective policy tools that will enhance inclusive childcare given that access to childcare is one of the factors enabling people on social assistance to make the transition to work.
- To meet these objectives, an extensive literature review was conducted, relevant policies and programs in Alberta, British Columbia, and Ontario were looked at, and in-depth interviews with 24 parents in the three provinces were conducted.

Literature Review

Literature pertaining to families who have children with disabilities who use social assistance was reviewed. The review focused in particular on transitions from social assistance to work, and barriers, including childcare, faced by parents. Particular emphasis was placed on literature regarding single mothers on social assistance/welfare seeking paid work, the care giving literature, and work/family literature.

Policy and Legal Analysis

Government policies, programs and legislation that affect transitions to employment for parents of children with disabilities who are on social assistance were analyzed. To this end, government communications on relevant programs and legislation were reviewed. The following areas such as social assistance, education, childcare, housing and social services were broadly reviewed in Ontario, British Columbia and Alberta. Government and agency reports, and interviews with senior agency personnel in each province provided information on how these policies and programs appeared to be working in practice, and identified key issues. The information available differed in all three provinces; a thorough review and comparison was constrained by the project budget.

In addition, current law, which pertains to childcare for children with disabilities whose parents are seeking labour force participation in the three provinces under discussion, was reviewed. Relevant case law was also reviewed (see Appendix A). In addition, the impact of the United States' *Americans with Disabilities Act*, a federal statute enacted in 1990, was explored. Attention was also paid to those broader Canadian statutes and constitutional provisions which dictate the manner in which specific statutes are implemented, both by the governments which create them and by the agencies which operate pursuant to them. This includes human rights legislation and such other statutes as those dealing with health care consent, employment standards, occupational health and safety, and the like.

Qualitative Interviews and Analysis

The research involved 24 informant interviews with parents on social assistance who

have children with disabilities. Twelve parents in Alberta/British Columbia participated and 12 in Ontario. These parents were, for the most part, contacted through agencies that provide support to such families.

Face-to-face interviews were conducted with participants. They were asked to fill out a questionnaire regarding demographic data, and to answer a range of (mostly) open ended questions from the interview instrument. (See appendix.) The interviewers followed the instrument, probing specific questions. Each interview lasted about two hours.

III.
SELECTED DEMOGRAPHICS

Parents of children with disabilities who use social assistance are a diverse group in terms of characteristics such as family styles, race and ethnicity, aboriginal status, immigration, language, lifestyle and beliefs. Every family is different, but as a group they share some common concerns with regard to accessing supports, overcoming poverty and barriers to employment. This study explores some of these common issues faced by families in this situation. It should be remembered throughout that some families face additional challenges posed by factors such a race, gender or other sources of discrimination, regional differences, immigrant status, language and so on.

While there is very little statistical data or literature that is specific to the situation of families of children with disabilities who are on social assistance, enough exists to indicate some of the characteristics of this group. Children with disabilities are a large and growing population. In 1991,[1] there were an estimated 534,430 children and youth aged 0-19 living in Canada who were disabled in some way. More recent estimates indicate that these numbers are even higher (CICH, 2000). Though estimates vary, between 5 and 20% of families in Canada have children with disabilities (Irwin and Lero, 1997).

There is some indication that families of children with disabilities are more likely than other families to be poor, and to rely on social assistance. Poor children are over 2.5 times more likely to have a problem with vision, hearing, speech or mobility than children in high-income families (Ross and Roberts, 1999). According to The Roeher Institute's analysis of the 1996 National Population Health Survey, nearly 17% of children with disabilities live in families who depend on government income support, compared with only about 8% of non-disabled children (The Roeher Institute, 2000). Furthermore, children with disabilities are more likely to be in families where the total household income is in the lower-middle to lowest income quintile[2] than other young people (28.8% compared with 17%). As a result, it is nearly twice as likely that families in this circumstance will run out of food money (15.8% had done so in the past 12 months, compared with 8.2% of other families). This is not to say that disability is simply the result of poverty. In many cases, families are struggling with poverty because they have a child with a disability.

The NPHS also shows that children with disabilities are over-represented in lone-parent families (18.1 compared with 14.1% of non-disabled children and youth aged 19 and younger) whether or not they are on social assistance (The Roeher Institute, 2000). The risk of poverty is higher for lone-parent families than for two-parent families. According to the National Longitudinal Survey of Children and Youth, just over 70% of children from lone-mother families lived at or below the official Low Income Cut-off (LICO) in 1994; in contrast, only 16% of children with two parents lived in low-income families. They are also more likely to depend on government income support than two-parent families (Statistics Canada, 2000). In the 1996 Census, almost all lone-parent families (97.5%) reported income from government transfers, 39% of which was social assistance. Overall, 26% of lone-

Table 1.

Comparisons of families of children with disabilities and other families (NPHS, 1996)

Family characteristics	Child Disability Status	
	With disabilities	Without disabilities
Dependent on government income support	16.9%	8.1%
Household income is in the lower-middle to lowest-income quintile	28.8%	17.0%
Ran out of food money in preceding 12 months	14.4%	8.1%
Ran out of money and received food from a food bank or soup kitchen in the past year	32.6%	28.7%
Lone-parent family	18.1%	14.1%

In 1994, over 70% of children from lone-mother families lived in poverty, compared with 16% of children who have two parents.

Nearly 40% of lone-parent families were on social assistance in 1996.

The vast majority of lone-parent families are headed by women.

Single mothers are twice as likely to be poor than single fathers, and more than four times as likely than families with two parents.

parent family income came from transfers compared with only 10% of income to husband-wife families (Statistics Canada, 1999).

The vast majority of lone-parent families are headed by women (Statistics Canada, 2000). In 1994 lone-parent families headed by women (56.8%) were nearly twice as likely to be poor than those headed by men (30.7%), and more than four times as likely as families with two parents (12.8%) (Canadian Council on Social Development, 1995). As such, it is expected that a much higher proportion of women than men are struggling to support children with disabilities while an overwhelming majority are women living in poverty and/or relying on social assistance.

Visible minority, recent immigrant and First Nations people are also likely to be disproportionately represented in this category of families, for a number of reasons. They are more vulnerable to poverty as a result of inequities and barriers that continue to exist in Canadian society. The Survey on Labour Force and Income Dynamics (SLID) shows that while all of these groups are at considerable risk of low income, people who are visible minorities, or First Nations are more likely to have low incomes. Among recent immigrants (after 1976) at least 15% experienced low income for four years, compared with 4% of those who were Canadian-born. Similarly, about 17% of visible minorities experienced low income on a continuous basis, compared with only 4% of people who are not visible minorities.

Furthermore, as a result of higher poverty rates in these communities, among other factors, the incidence of disability may be higher in these communities than in others. For example, First Nations people are twice as likely as other Canadians to be disabled (30% compared to 16% in 1991) (Federal/Provincial/Territorial Ministers Responsible for Social Services, 1998). Although there is limited Canadian research, this is well documented in American and international literature (Bowe, 1984; Hayes-Bautista, 1992; Thornhill and Hosang, 1988; U.S. Department of Education NIDRR, 1992; U.S. Department of Health and Human Services, 1985a, 1985b, 1991; all cited in Smart and Walls, 1997; Pichette, Berven, Menz and La Fromboise, 1997, OECD, 1992). First Nations and visible minority children may also be more likely to be labelled as having certain kinds of disabilities as a result of culturally biased testing and discrimination. For example, Smart and Well (1997), show that African-American children are more likely to be labeled as having an intellectual disability than American children of European descent (26% compared with 11%).

Families of children with disabilities live in rural and urban areas. However, children aged 11 and younger with disabilities are more likely than non-disabled children in this age group to live in rural areas of the country (39.9 compared with 32.2%, respectively). After the age of twelve, possibly in pursuit of services, many families seem to move to urban areas. The proportion of all children with disabilities living in rural areas who are older than 12 years old drops to 23.2%. For non-disabled young people in the same age group, 36.3% continue to live in rural areas (The Roeher Institute, 2000).

First Nations children with disabilities may be living on reserves or off reserves. As with other children with disabilities, where their family chooses to live may be affected by availability of services. On-reserve services are funded by the Federal Government and by each Band or First Nations Government. There is great variability between reserves in terms of the types and level of services available, but, generally speaking, families living on reserves have fairly poor access to disability-related services. Off-reserve services are funded by provincial and territorial governments. Provincially funded services provide greater support for families living off reserves, but families then lose access to other types of Band support, such as housing. First Nations children and families also may or may not have "Indian Status," or band membership, factors which could have significant impact on their access to health-related and other supports.

The probably higher than usual proportion of women, people who are visible minorities, recent immigrants and Native People in this group should be taken into consideration in developing policies to address the needs of this group. All of these groups contend with barriers associated with gender or race as well as disability and poverty, yet policies and programs have not been designed to meet their specific needs.

Endnotes

[1] These statistics are from the Canadian Health and Activity Limitation Survey (HALS), conducted as a follow-up to the 1991 Census. More recent statistics are not available, since HALS was dropped from the census survey following that year.

[2] An income quintile represents the income range for one-fifth of all household incomes. If we take all households and rank their incomes from highest to lowest, then equally divide the number of households by five, family incomes fall into five broad groupings. Families who fall into the highest and lowest groupings represent the "highest" and "lowest" family incomes in the five-point scale. Other families and their incomes fall into the lower-middle, middle and upper-middle groups.

IV.
LITERATURE REVIEW

A fair amount of social assistance literature explores the situation of adults with disabilities who use social assistance. Similarly, a significant body of literature points to the number of single parents, particularly mothers, facing barriers to labour force inclusion. However, strikingly little attention has been paid to the situation of parents who have children with disabilities and who wish to participate in the labour force. The care giving literature addresses at length the emotional support needs of parents of children with disabilities, yet rarely raises issues of labour force inclusion for these parents. Similarly, few articles focus on the challenges of parents of children with disabilities juggling their multiple responsibilities. Furthermore, work/family literature focuses predominately on the challenges of middle-class parents, paying little attention to the needs and circumstances of low-income families. Articles focusing on the challenges of parents of children with disabilities juggling their multiple responsibilities are few but growing in number. There is next to nothing in the literature regarding labour force issues faced by parents on social assistance who have children with disabilities.

Parents, particularly mothers, with children who have disabilities are caught in the middle of several current trends. While previous generations have been encouraged to institutionalize their children with disabilities, most families now want, and society expects them, to care for their children at home, despite limited supports to do so. During the last decade the survival rates of babies with exceptional health care needs have increased dramatically due to advances in medical science and technology. Subsequently, the numbers of families providing care has increased, and the duration of this care has lengthened (Norton, 1993). At the same time, the roles of women have shifted and expanded. As women's rights to participate in the workforce are increasingly recognized, a societal expectation of self-sufficiency for women has evolved that fails to pay attention to their continued responsibilities in the private domain. Women continue to be expected to provide the types of care giving and domestic duties they performed traditionally, and to earn money in the public domain. Many women find balancing these multiple roles challenging, but it is particularly an issue for women on social assistance with school-aged children and younger (Ellwood, 1996), especially if their children have disabilities, and the necessary supports (e.g., childcare) are not in place.

The Literature on Social Assistance

The 1980's and 1990's have seen a dramatic rise in poverty and dependence of individuals and families on social assistance. *Report from the Forum*, a British Columbia government review of the social safety net, notes that between 1981 and 1991 the rate of poverty among young families almost doubled, rising from 21% to 37%. Through the 1990s this trend accelerated with dramatic increases in rates of child poverty. According to the Canadian Council on Social Development (2000) in 1997 there were 50% more poor children than in 1989. The Council also points out that a child's chances of

living in poverty in the 1990's increased if they lived with young parents, a lone parent, or if their parent was a member of a visible minority group.

The B.C. report attributes increases in poverty and dependence on income security programs to a number of social trends, including:

- Technological change
- Economic globalization
- Federal fiscal and monetary policies
- Closed labour market
- Changing family structures
- Reduced welfare stigma
- Disincentives to work

A major review of social assistance, entitled *Transitions*, undertaken by the Ontario Ministry of Community and Social Services in 1988 suggests that in the preceding 20 years the causes of poverty have changed dramatically. This report specifies the following causes of poverty:

- Changes in family composition
- Increases in family breakdown
- Rapid growth in single-parent families
- Deinstitutionalization and integration of disabled people
- Changing conditions in the economy and employment prospects for those with limited skills
- Declining stock of affordable housing

These reports and others like them are largely sympathetic to the challenges faced by people who find themselves on social assistance and/or homeless, as is reflected in this quote from *Transitions*:

> *In most instances, the homeless — whether a woman leaving an abusive spouse, a person discharged from an institution, or a recently unemployed family head with limited skills — were overwhelmed by major life crises and unable to secure the necessary community supports to regain control of the rest of their lives. Most of these people, prior to the trauma that turned their lives upside down, were much like the rest of us. The difficulties and problems that disrupted their lives could happen to any of us. We all face risks of family breakdown, of losing a job, of chronic illness or disability (p. 69).*

The reports point to barriers faced by people who are trying to gain control of their lives, such as discrimination, lack of workplace supports for disabled people, no affordable childcare, a lack of affordable housing, low wages, lack of training/education, lack of transportation, and the hidden costs of working. The literature is specific and comprehensive in terms of what supports are required for social assistance recipients to become self-sufficient as well as what government policy and programs should be put in place to facilitate this goal.

Although the extensive recommendations contained in such reports were never fully implemented, these documents at least represent a certain approach and attitude towards those in need. Beginning in the 1980s in the United States during an era of conservative "think tanks," there was a dramatic shift in attitude. Social assistance programs began to be viewed as the source of domestic socialism and dependency. Increasing emphasis was placed on the dangers of welfare for families. While many social scientists have tried to counter this movement and have been strongly critical of it, others apparently laid the basis for this shift in thinking, arguing that the social safety net was itself the source of social problems among recipients, and that welfare programs should be eliminated or rendered punitive and work-oriented for the poor. The literature indicates that the 80s signaled an end to a commitment to the ideals of a liberal welfare state, however limited and unequal it may have been, leading to a political climate where ideas dismissed as

extreme for half a century could win mainstream legitimacy. (Withorn,1996). What has been noted in the rebuttal literature, is that current policy initiatives, such as the U.S. president's declared commitment to "end welfare as we know it," seemed to have been carried out with disregard to everything we know about social assistance and poverty. Indeed, while most social scientists have tried over the years to counter the stereotypes of the lazy, unmotivated, work-averse welfare recipient, it would seem that current governments are taking advantage of these stereotypes to win public support for punitive and, much of the literature would argue, ultimately counter-productive policies which leave children and families entrenched in deeper poverty (Aaronson and Hartmann, 1996).

What began in the United States moved northward in the 1990's. In Canada, a similar shift in thinking was driven by Canada's monetary report, World Bank loans and new priorities for deficit reduction. This happened throughout the country, though changes have been more pronounced in Alberta and Ontario. The result has been substantial changes in government policies and an intensification of political debate.

Ontario, in particular, has made a definitive departure from previous approaches and government documents. For example, the 1988 Ontario review of social assistance recommended that workfare remain prohibited.[1] The rationale given was that workfare had not been demonstrated to be effective in other jurisdictions, and was seen to perpetuate the myth that people on social assistance do not want to work and must be forced to do so (p. 69). Nonetheless, the Ontario government of the '90s has proceeded with a workfare program as well as extensive legislative reform to the social assistance program.

There is, in fact, considerable disparity between the approach of social science literature and that of government policy through this period. It is worth noting that *Transitions* [2]as well as other literature (e.g., Parker, 1994) advocated that there be a media campaign to raise public awareness about the realities of people on social assistance, to garner public support for more progressive, supportive and effective policies. While the 1988 report as well as other literature (Parker, 1994) emphasized the proven importance of supporting and ensuring recipient autonomy as a way of ensuring long-term self-sufficiency, current legislation undermines autonomy. For example, it allows, in some instances, denying the right of recipients to pay their own bills. These changes, however, do not appear to be based on the literature. When requested by The Roeher Institute to provide the background literature used in developing legislative and program changes since 1995, the Ontario government produced only their election platform statement, *The Common-Sense Revolution*.

One of the most notable changes in attitude and policy pertains to single parents (mostly mothers) on social assistance. In the past, it was assumed that single parents, along with the chronically ill and disabled, were among those who could not be reasonably expected to work. *Transitions,* while identifying single parents as a group in need of special "targeting" to facilitate a return to work, also emphasizes the belief that, "sole-support parents must have the option of staying at home to raise their children if they so choose. Raising young children, in our view, is every bit as important and useful a contribution as participating in paid employment" (p. 339).

The '90s in Canada have seen a dramatic change in attitudes towards single parents. In a number of provinces, mothers of school-aged children are expected to work. In Alberta, single parents of children more than six months old are expected to work. Neither single-parent families, nor families with children (let alone parents of children

with disabilities) were exempted from Ontario's welfare cuts of 21.6%. Ironically, while the pressure on poor mothers to work has increased, there has been growing pressure to compensate spouses who are well off enough to stay home with their children.

A shift has happened at the federal level as well. When public opinion polls indicated a lack of public sympathy for single parents, the current government chose to make child poverty the issue. The assumption seemed to be that this would receive wider acceptance rather than attempting to counter the myths on which growing public antipathy was based. This approach obscures the reality that children are poor because their parents are poor. Still, even approaches to child poverty have been inadequate. The federal government created a child benefit, but it is not available to all children on welfare, as the agreement with the provinces allows them to claw it back. At present, all do so with the exception of Newfoundland and New Brunswick. However, this may change as the value of the Child Tax Benefit increases over the years, and these provinces may follow the others in implementing a claw-back.

With the overall increase of women in the work force, some employers and policy makers have become more aware of the need for family-supportive benefits. But as the literature points out, this understanding or the benefits themselves have not necessarily been extended to women on social assistance, or to women earning low incomes. (Spalter-Roth, Hartmann and Andrews, 1992; Parker, 1994). "Instead these women are perceived as undeserving poor (Glazer, 1993) whose lack of self-control and motivation are to blame for their poverty" (Abramowitz, 1995; Axinn & Hirsh, 1993 in Piotrkowski, and Kessler-Sklar, 1996). Poor mothers have become targets of blame for a range of social ills, from drugs, through adolescent crime, to deteriorating neighborhoods and the national deficit (Speirs, 1998). Commenting on the new welfare law in the United States, one writer says, "The new welfare seems to have been created from an outmoded fantasy about male breadwinners. The real context of poor women's lives was not factored into the equation." (Califano, 1996, p. A23) This turn of the tide with its "scathing stereotyping of poor mothers has had severe consequences for their children, and for society as a whole" (Sidel, 1996).Yet, the literature has clearly established that single mothers on social assistance wishing to participate in the paid work force (and the majority do want to work) face extensive and formidable barriers on all fronts. The 1988 Ontario government report stated, "Time and time again we heard from sole-support parents who expressed their desire to be self-sufficient. Many want to work but they identify the lack of adequate, affordable, and flexible childcare as their greatest impediment" (Ontario Ministry of Community and Social Services, p. 318).

Childcare has been identified throughout the literature on social assistance/work transition, as a major issue (Meyers, 1995; Smith, 1995). More recent literature indicates that poor women face additional psychological and practical hurdles to being able to work. Studies of American women on Assistance for Families with Dependent Children (AFDC) indicate that 92% of them have been severely assaulted, with the majority suffering from post-traumatic stress syndrome (Salmon, 1996). Furthermore, an emerging body of research indicates that a woman's attempt to work may be seriously obstructed by an abusive partner (Raphael, 1996). Yet policies directed at ending dependence on social assistance for the most part fail to address the effects of violence in the lives of poor women, and its impact on their capacity to work and to sustain trusting and supportive relationships (Browne, 1993a, 1993b; Herman, 1992).

Other factors affecting and predictive of employment include the level of education, previous work history, positive parental role

models, income from an alternative source, delayed childbirth, the number of children, adequate housing and supportive workplaces (Brooks and Buckner, 1996). Poor women are usually limited to low paying jobs, and the literature shows that work attachment is likely to be affected by the structure of opportunity and constraint in the workplace, family, and the community (Bielby, 1992, Voydanoff, 1987).

Not surprisingly, jobs that involve little skill, economic reward, autonomy, or opportunity tend to produce unambitious, uncommitted, high turnover workers (Oliker, 1995). By the time they have factored in the additional costs of working (clothes, transportation, health care and so on), single mothers may conclude it is impractical and economically illogical to work (Brooks and Buckner, 1996). However, rather than actively addressing the barriers to work that leave social assistance recipients to conclude they are better off on social assistance, the response of some current governments seems to be to make life on social assistance as unattractive as possible (*The Toronto Star*, 1998), through, for example, reducing benefits or eliminating them altogether. Conversely, little has been done to make working a more attractive and realistic option. Indeed, in Ontario, the minimum wage has been frozen since 1995.

Implications for Parents of Children with Disabilities

Parents of children with disabilities are, for the most part, invisible in the literature on social assistance. *Transitions* only makes brief mention of Ontario's Handicapped Children's Benefit (which they recommended be separated from family benefits) and a passing reference to the connection between homelessness and developmental disabilities. The otherwise comprehensive document makes no other mention of children with disabilities and the impact on the parents who care for them. Nor does the more recent British Columbia report, an Ontario study profiling social assistance recipients (Omstein, 1995), or several reports of the National Council of Welfare. Even a special issue of the *American Journal of Orthopsychiatry*, devoted to "Welfare Reform and the Real Lives of Poor Women,," published in the wake of the new American 1996 welfare law, makes only one related reference. It notes that families living in poverty that include individuals with disabilities are in even greater jeopardy given the dramatic cuts in welfare spending (1996, p. 484).

It has long been accepted that lone-mother status and poverty itself may be a contributing factor to the likelihood of childhood developmental disability and/or ill health (Ramey and Ramey, 1992). In addition, single parents have been shown to be significantly at greater risk for financial problems, stress and depression (Turnbull and Turnbull, 1990).

What is less considered in the literature is that the burden of caring for a disabled child, without sufficient support, may itself lead a family to poverty and dependence on social assistance. Rates of disability are five times higher in families with lowest incomes compared with highest incomes (McKeever, Angus and Spalding, 1998). Parents face significant costs related to disability, both from reduced income and benefits due to time loss from employment and to the additional costs they must pay, such as for tutors, special diet, special clothing, transportation, babysitting, medications, supplies and equipment, and home adaptations. (McKeever, Angus and Spalding, 1998; Ambert, 1992). One American study showed the families of children with disabilities have higher out-of-pocket costs than families without. The average cost for such families was an estimated $6,348US, and the percentage of household costs increased significantly as family income decreased (Fujiura, Roccaforte, and Braddock, 1994).

Furthermore, many women end up on social assistance as the result of marital breakdown. Marital breakdown is even more likely given the stress and strain sometimes associated with caring for a child with a disability (Irwin and Lero, 1997). The time and complex responsibilities involved in caring for a disabled child in itself often preclude working full-time or even part time. In families where one parent (usually the mother) has given up employment altogether, the family is particularly vulnerable should the other parent lose his/her job. Similarly, while the level of education is a factor in someone remaining on social assistance, parents of children with disabilities often are forced to forego opportunities to upgrade skills and education or advance their career. Studies have found that caregivers of children with disabilities are less likely to be in paid employment and are more likely to work part time, earn less money and reduce the hours they work or take a leave of absence to care for their children (Akabas and Krauskopf, 1984; Baldwin and Glendinning, Staruch, 1982; Gallimore, Weisner, Bemheimer, Guthrie and Nihira, 1993).

While issues like childcare are of major importance to all single parents who want to enter the labour force, single parents who have children with disabilities are likely to face even greater obstacles in finding appropriate and affordable childcare (Akabas and Krauskopf, 1984; Irwin and Lero, 1997). Similarly, while finding employers (particularly in low-end jobs) willing and able to accommodate the needs for flexibility of a single parent is a challenge for all single parents, it is even more so for the parent caring for a child who may require numerous medical appointments and unpredictable medical emergencies. Furthermore, if loss of medical coverage, including dental and drug plans, is a concern in going back to work for parents of children without disabilities, needless to say it is bound to be an even greater concern for parents of children with disabilities. If single parents in general are more dependent on extended family, and at the same time constrained work-wise in terms of reciprocal obligations (Oliker, 1995), then, most likely, parents struggling to care for children with disabilities are even more dependent on such support, and in more difficult circumstances if it is not available.

None of the literature deals with the full range of psychosocial and practical realities facing parents of children with disabilities who are on social assistance, and who may be single parents. Therefore, there is no one piece of literature that gives a truly full and comprehensive picture of the challenges for parents in this situation. For example, women on social assistance who have children with disabilities are a portion of the 92% cited above who have endured serious violence and suffer severe mental distress. Given that children with disabilities are much more likely than other children to suffer all forms of abuse, the parent may also be dealing with a disabled child recovering from abuse. Single parents of children with disabilities also form a proportion of the single parents suffering depression. What are the implications for families when these complicated factors are introduced?

Given the above, and the greater vulnerability of families of children with disabilities to factors that contribute to poverty, the proportion of parents on social assistance who have children with disabilities may well be greater than the general population. As was noted earlier, between 5 and 20% percent of families in Canada have children with disabilities (Irwin and Lero, 1997). Yet nearly 30% of all families in the lower-middle and lowest-income quintiles have children with disabilities, according to the National Population Health Survey (Crawford, 1999).

A recent American study further confirms this. Researchers at the Urban Institute found that between 27.4 and 29.5% of

families receiving Assistance for Families with Dependent Children (AFDC) have either a mother or child with some level of functional limitation. They found that between 11.1 and 15.9% of the families had children of all ages who were limited in the kind or amount of their activity. These estimates were considered conservative (The Urban Institute, 1998). Unfortunately, similar data in Canada are not readily available.

If the number of families who have children with disabilities on social assistance is substantial, then the inclusion of their issues in the literature on social assistance is all the more urgent. The omission of these families in the social assistance literature, as well as their absence in government documents, on which social assistance policy is largely based, has very serious implications for the ultimate well-being of children with disabilities and their parents. Their situation is more likely to be ignored when welfare rates are cut, particularly in an atmosphere of growing animosity towards people using social assistance.

In a recent small study of five homeless families living in a shelter in Metro Toronto, three had children with learning, developmental and/or mental health disabilities. All of the children had adjustment problems and suffered regression due to their change in circumstances (Anstett, 1997).

In the United States, in less than a year, at least 145,000 children with disabilities from low-income families were cut off Social Security Benefits. Another 250,000 children with disabilities have been denied benefits they were seeking because their families live far below the poverty line (Kenna, 1997). While many of these refusals were appealed, such actions have, nonetheless, been viewed by advocates for children with disabilities as alarming. Jonathan Stein, General Counsel for Community Legal Services of Philadelphia, which is leading a national campaign to overturn Supplemental Security Income judgments, commented:

> *"It bespeaks a societal malaise. This is a metaphor for the mood of America, when even disabled kids become the target for budget cuts... It really speaks to where we are as a society. This is what we've come to – Tiny Tim is now the target" (Kenna, 1997).*

The Care-Giving Literature

The care-giving literature provides important information about the various care giving challenges that parents of children with disabilities face. However, it has almost little to say about the basic fact that most parents of such children, including mothers, either work or need to work and face substantial obstacles in doing so. The focus tends be on issues such as emotional and practical support in parenting, and how best to support the child. Most agencies do not deal with the multiple roles parents must play in relation to the disabled child and other aspects of their lives. Agencies rarely or never address strategies to ease parents' challenges in finding or maintaining work (Irwin and Lero, 1997).

Balancing Work and Family

Work/family conflict is an increasing problem in Canadian society. Dr. Linda Duxbury (1996), a key Canadian researcher in the area of work and family, attributes this to a number of factors. She suggests that not only are the traditionally separate worlds of work and family merging, there has been a significant increase of women in the labour force. The biggest change is the number of women with children under the age of six who are now working outside the home. Further, from the '70s to the present, the proportion of women working with children under the age of three has doubled. Yet there is a lack of adequate childcare. Only 18% of Canadian children requiring childcare are cared for in licensed facilities. Duxbury

explains that workplaces are not responding to these changes. In fact, workplace pressures and the time spent at work are actually increasing. A trend toward downsizing in workplaces introduces greater economic insecurity and stress for workers and a conspiracy of silence among downsizing survivors. That is, survivors of downsizing are too worried about job security to complain about increased workloads. Added to this is the increasing numbers of workers caring for elderly parents, which gives rise to the birth of the "sandwich" generation, namely, workers who are caught between the demands of caring for a young family and the demands of caring for aging parents.

According to researcher Bradley Googins, the problem is that while tremendous changes have happened in terms of demographics, economics and values in our society, the structures that have been set up were predicated on a "Leave it to Beaver" model. Workplaces, schools, services, and government continue to operate on the basis that there is someone at home taking care of everything. This has created difficulty and stress for families, now the majority, where both parents are working. He commented in his study that:

> *The one characteristic that was repeated throughout the interviews was the prevailing sense of tiredness, a generation of fatigued, exhausted people who accepted their dependent care responsibilities gladly, but had either run out of strategies for successfully integrating work and living, or given up out of desperation" (Googins, 1991).*

Some researchers note that not only are more and more families taking on the double roles of responsibilities in the public (work) and private (home) domains, expectations that community members, particularly women, provide unwaged work, previously provided through government services, is also on the rise. McKeever, Angus and Spalding (1998) outline how this expectation increasingly forms the basis for health and welfare policy. A mixed economy of care is developing in response to escalating costs of health and social services. Long-term care facilities are being closed or converted to provide outpatient or ambulatory care centres, and community-based services are replacing institutions. However, because community-based services are not keeping up with the demand, families are expected to fill the gap.

Women continue to provide unpaid caregiving work. The 1996 Census data show that women tend to take on the bulk of unpaid work in communities, and much of this is in caregiving (Status of Women Canada, 1998). There continues to be a notion in society that women share some common trait that makes them most suited to be nurturers and caregivers, though feminist researchers and theorists show that social, economic and cultural pressures socialize females to fulfil these roles (Rubin, 1975; see also Haraway, 1991). Women are censured if they reject the role. They are pressured to accept these roles and to forgo opportunities for themselves in order to fulfil traditional responsibilities, thus compromising their citizenship.

When they have children with disabilities, the kinds of unpaid work that women do is often highly skilled, requiring the combined professional skills of nurses, teachers, therapists and administrators. They often make a "career out of caring" (Wickham-Searle, 1992), performing tasks that were formerly the realm of paid professionals (Haverstock, 1992; Ambert, 1992; McKeever, Angus and Spalding, 1998). Yet they are unpaid, considered unskilled, have no vacation leave, no sick benefits, no workers' compensation, and no safety standards. They work on call constantly and live where they work (McKeever, Angus and Spalding, 1998; Ambert, 1992; Guerriere and McKeever, 1997).

Responding to these expectations have negative impacts on women. The labour

force participation of mothers of children with disabilities is delayed or restricted (The Roeher Institute, 1998; Booth and Kelly, 1999), and they are described in the literature as anxious, sad, burdened, exhausted, socially isolated, lonely and lacking in self-esteem (McKeever, Angus and Spalding, 1998). They report high physical and psychological stress, chronic fatigue, headaches, menstrual problems, digestive problems, depression, anxiety, interrupted sleep and irritability (Ambert, 1992; Guerriere and McKeever, 1997; McKeever, Angus and Spalding, 1998). Bakker (1998) describes some of the negative economic effects for society more generally from unpaid work including loss in women's time use and opportunity, tax contributions, and increased demands on social services.

While these realities have implications for lower-income as well as middle-class families, the literature to date has largely focused on the struggle to juggle multiple responsibilities among the middle class. If middle-class families without children with disabilities are fatigued and exhausted, it is probable that poor families with a disabled child will be even more so. Furthermore, as acknowledged above, there is a dearth of literature addressing the realities of working parents (particularly lower income) who are also caring for children with disabilities.

One notable exception to this is a recent Canadian publication, *In Our Way: Childcare Barriers to Full Workplace Participation Experienced by Parents of Children With Special Needs — and Potential Remedies.* This report, by Donna Lero and Sharon Irwin (1997), points out at the outset that:

> *While all families face significant issues in managing paid work and family responsibilities, this [report] indicates that parents of children with special needs are not on a common, level playing field with others. These parents face many additional challenges, often with few appropriate, ongoing supports. To date their needs have not been recognized — let alone addressed.*

These "additional challenges" include factors such as:

- Childcare and related costs which are generally much higher for their children with disabilities
- Lack of additional supports, such as special training, equipment and personnel for childcare programs, which means that the doors to regular childcare programs are closed
- Spouses (usually the mothers) often having to leave the workforce or take part-time work because of additional needs
- Children's medical needs are unpredictable and more intensive, thereby often requiring much more time off work and many more uninsured expenses.
- Caring for a disabled child requires additional time to access and co-ordinate services, as well as to take the child to numerous appointments.

Another recent article supports these findings with respect to parents of children with developmental disabilities. In this article, Freeman, Litchfield, and Warfield (1995) comment:

> *What seems to distinguish families of children with disabilities from other working families is the intensity and complexity of the arrangements required to balance work and home responsibilities successfully.*

They then suggest that the supports and arrangements of these families are more tenuous than in other families, and that there is greater worry about whether the support system will endure. This leads to reluctance on the part of parents to make changes in their careers or place of work because they fear they might jeopardize the existing work/family balance.

While it is important to address the need to create employment opportunities and supports for such parents, researchers caution

that this is not the only solution. There is also a need for policies to recognize and compensate the unpaid work that women and others do. McKeever, Angus and Spalding (1998) recommend that caregiving be conceptualized in policy as work so that compensation and working conditions can be considered. For example, they suggest parents caring for children with disabilities have access to occupational health components, such as lifting techniques and improved working conditions through funding adequate home adaptations and amenities. Their findings suggest that respite, emergency and vacation care are essential. Policy makers also need to pay attention to, and address, circumstances that require women to perform the bulk of unpaid work involved in caregiving.

The impact of employment on parents of children with disabilities has been documented in this limited body of literature. Parents may choose an occupation that is less demanding, forego promotions and career opportunities (and the increased earnings), and curtail their hours of paid work in order to accommodate the additional demands required.

In the Irwin and Lero study, when parents were asked directly whether having a child with a disability had affected their jobs, 31% of the employees surveyed said their own employment status was affected, 27% had been constrained and 44% reported that their work schedule is affected by their child's needs. Interestingly, a high percentage of the working couples in this study were able to juggle the additional responsibilities by working different shifts. However, in 27% of families, one parent is not gainfully employed, and of this number three-quarters stated that the child's disability was the main reason for the parent to leave the workforce (p.137).

Where situations require that one spouse restrict employment, or stay home full time to care for a disabled child, it is usually the mother who does so (Irwin and Lero, 1997). While fathers may be involved with the care of their children, and are certainly affected by concerns about the well-being of their children (Greenberger and O'Neil, 1990), it is noted in the literature (either directly, or in the assumptions on which the literature itself is based) that caring continues to be viewed primarily as a woman's responsibility (Traustadottir, 1991). The resulting reduced career opportunities and earning power of mothers in this situation contribute to the economic vulnerability of the family. If her capacity to contribute financially is thus reduced, the likelihood that the family will face economic hardship down the road should they encounter unemployment, marital breakdown, illness or other family crisis is increased.

For those families who juggle paid and unpaid responsibilities, as Irwin and Lero suggest, the day-to-day struggle to balance work and family takes a toll:

> *Very high levels of physical and emotional fatigue, very high stress, and much tension balancing work and family responsibilities together paint a very troubling but probably accurate picture of this group of employed parents of children with special needs. Left on their own with continuing pressure, limited flexibility, and limited support, they are a population at high risk of ill health, marital stress, and burnout. Many make every reasonable effort to protect their job and do good work — but the costs can be very high, and certainly are inequitable (p. 77).*

A number of factors, most importantly the type of disability and the presence of child behaviour problems are linked to the level of parental stress and care demands (Floyd and Gallagher, 1997). For example, the literature indicates high rates of behaviour disorders and psychiatric problems among children and adults with developmental disabilities (Gruffman and Themner, 1986). So, too, children's needs may change over

time and/or new challenges may emerge. The stress level in most of these families is disturbingly high. Irwin and Lero found that 88% of their sample reported feeling tired, 90% reported feeling stressed about work/family balance, while 93% reported a moderate to severe tension level in day-to-day living (p. 76).

While the literature points to the various obstacles faced by parents of children with disabilities in the work place, it is worthwhile noting that it also indicates that work plays a vital and positive role in the lives of these families. Not only does work provide financial remuneration and health benefits, but it also provides a source of psychological fulfilment, respite and control over their lives (Freedman, Litchfield, and Warfield, 1995).

While much of the literature focuses on negative impacts of caring for children with disabilities, it is important to note that parents also find caregiving deeply rewarding and satisfying (McKeever, Angus and Spalding, 1998; Ambert, 1992). Parents describe finding a "new appreciation for life" through their relationships with their child (Guerriere and McKeever, 1997), develop adaptive coping skills, such as acceptance, positive reinterpretation and growth, spiritual strength, and planning skills. In one study, mothers of adults with disabilities were described as women who actively engage with life's problems (Wyngaarden, Krauss and Mailick Selzer, 1993). In literature exploring parents perspectives, parents are clear that the negative impacts they experience are caused by lack of support (McKeever, Angus and Spalding, 1998), and the fragmented, inflexible, inaccessible, and inconsistent service system (Hoare et al., 1998; Sharpley et al., 1997; McKeever et al., in press), not their child or their child's disability.

Single Parents

If the work/family literature is limited when it comes to parents of children with disabilities in the workforce, it is even more scant regarding single parents in this circumstance. In most of the literature single parents are barely mentioned if at all. However, what is said about them is significant in terms of implications for policies and community supports if single parents of children with disabilities, currently on social assistance, are expected to join the workforce. Single parent families, even more than two-parent families, are strongly affected by the availability of supports, and are more dependent on them. If a single parent cannot obtain suitable assistance — in meeting familial needs, sustained participation in the labour market is unlikely. In effect, that parent already has a full-time job, even if it is not recognized as such (Irwin and Lero, 1997).

Employed parents in two-parent families may sometimes benefit from multiple roles of domestic and labour force responsibilities, probably by supporting each other. However, single parents, particularly those who have children with disabilities, are likely to be more vulnerable to role overload and burnout. It is noted that service providers (and others) need to be aware of the vulnerability of such parents, particularly when serious behavioural problems accompany the child's disability. In general, single parents of children with disabilities appear to be at risk for depression and reduced psychological well-being. This risk appears especially true for those parents who do not have an involved co-parent, and who are either not employed or who are the primary provider with no other source of income (Gottlieb, 1997).

Key Barriers to Workforce Participation

Families caring for children with disabilities share a number of barriers to workforce participation, including lack of affordable, accessible childcare; inflexible workplaces; the extraordinary costs of caregiving; and

fear of loss of benefits such as medical and dental coverage. Many parents face additional barriers due to discrimination and systemic disadvantage related to race, culture, language, geographical location, gender or other characteristics.

Childcare

Despite these findings, the availability of subsidized childcare remains limited both in the United States and Canada (with the exception of Quebec). The challenge of finding flexible, affordable and suitable childcare is a constant theme both in the social assistance and the work/family literature. But, for low-income families who have children with disabilities, it is a particular challenge.

Quality, accessible childcare is an important factor in labor force inclusion for parents on social assistance. The literature on support needed for women on welfare seeking workforce participation indicates that 25% of young unemployed mothers are out of the labour force because of lack of childcare support. Various studies are strongly supportive of the positive impact of subsidized childcare on the likelihood of women returning to the workforce. The U.S. General Accounting Office (1994b) estimates that fully subsidizing childcare could increase the proportion of poor mothers in paid employment from 29% to 44%. Kimmel (1994) estimated that childcare subsidies would increase labour force participation among single-parent welfare recipients from its current level of 12% to 38% (Meyers, 1995). A recent study of 765 single mothers on welfare by McMaster University in Ontario found that good free childcare (and recreation programs) enabled these parents to leave welfare at twice the rate of the welfare population not receiving such assistance. It also dramatically improved their psychological sense of well-being and reduced their use of more costly social services (Browne, 1999).

Much of the literature focuses on childcare for preschoolers. Parents of preschoolers typically face difficulty in accessing childcare. As noted above, the number of licensed spaces in Canada accommodate only 18% of the number of children requiring childcare overall (Duxbury, 1996). Other parents must make informal arrangements in order to work, attend school or training programs. The limited availability of childcare spaces, in both urban and rural areas, and the tenuousness of more informal arrangements, is a source of great stress to many Canadian parents, which has been well documented in articles, briefs, and reports.

For many parents, however, access to childcare outside of school hours is also an issue, particularly if they have children who are disabled. Lack of childcare after school, before school and in the evenings can impede workforce participation, particularly for parents who may do shift work. A recent study by The Roeher Institute, which surveyed 50 families of children with disabilities, found that only 12% of the parents reported having access to after school care. Parents cited barriers to after school care including unavailability of such services at their child's school, high costs of private services, difficulty finding reliable and qualified care, and lack of disability-related training among staff who provided care for children of this age (Roeher Institute, 2000).

Parents with older children face particular difficulties in finding care. Licensed childcare for children over 12 years of age does not exist. This often results in parents of children over 21, who have worked for most of their children's life, having to make the difficult choice to stay at home to care for them because they are no longer served by the school system. Effectively, these parents have been forced out of the workforce.

Whether a family finds suitable and affordable care for a child with a disability is

subject to the willingness and ability of the individual centre or caregiver to accommodate the child's disability-related needs (Roeher Institute, 1992). Some childcare centres have made it a policy to be inclusionary and not to turn away any child. However, many other centres may be forced to deny some children access, simply because they do not have adequate facilities or staff ratios to meet the child's needs. This is particularly true if the child demonstrates behavioural problems (Irwin and Lero, 1997).

Parents of children with disabilities across the country may encounter certain obstacles in seeking childcare. Some of these issues may also affect parents more generally. The issues have been outlined by The Roeher Institute (1993) and Irwin (1992). They include:

- Lack of a clear policy and mandate that makes childcare, particularly inclusive childcare, a priority at all levels of government
- Lack of adequate capital and operational funding for childcare centers, and staff which, in turn, affect the quality and availability of care
- Care that is fragmented and inconsistent
- Long waiting lists
- Discretionary admission criteria set by individual programs, making it hard for children with disabilities to participate
- The high cost of childcare (especially if not subsidized), in addition to disability-related costs of diapers, equipment, special diets and the like, and time away from work to attend countless appointments
- Lack of transportation in both rural and urban areas, particularly when the child is not in a neighbourhood centre, or whose disability limits mobility
- Programming that does not respond to families' needs because of inflexible hours of service or a rigid childcare curriculum
- Insensitivity to issues of language and culture
- Inadequate professional training of childcare workers regarding disability issues.

An American study reported that adults parenting a child with a disability often encountered work-related problems due to difficulties concerning childcare arrangements. These difficulties arose when parents had to quit their jobs, refuse promotions, experienced high degrees of stress, had to leave work early, arrived late for work and returned to work much later than planned after the birth or adoption of a child (Fink, 1991).

In their study, Irwin and Lero found that 73% of the parents had difficulties finding appropriate care for their child. Seventy per cent had difficulty finding trained and committed caregivers, 68% have or had difficulty finding back-up care when an existing arrangement broke down or a child or parent fell ill. Care by the other spouse (either a partner not in the workforce or one who works shifts) was the primary care, but not necessarily the preferred arrangement for the majority of couples in the Canadian Union of Postal Workers sample. A significant number of parents worried about their current arrangements in terms of how long they would last, and what to do should the arrangement fall through (Irwin and Lero, 1997).

If childcare is an issue for two parent families, then it goes without saying that it is a particular problem for single parents of children with disabilities. They are likely to be even more constrained by a lack of spousal backup and financial considerations. The literature on social assistance underlines the importance of childcare in enabling single parents to achieve economic independence. A further small, but consistent, body of work/family literature addressing parents of children with disabilities emphasizes how crucial childcare supports

are. Yet, literature examining the particular difficulties childcare poses for a single parent with a disabled child, particularly one with a low income, was not found.

Flexible Workplaces

As the work/family literature indicates, nearly all parents can benefit from flexible workplaces in order to reduce work/family conflict and stress and fulfil their duties both as workers and as parents. All working parents must balance their parental responsibilities with the demands of the workplace (e.g., caring for sick children, responding to their children's unpredictable emergencies, meeting with teachers, and attending medical and dental appointments.) Such responsibilities are more easily accommodated if working hours are somewhat flexible and there are generous leave of absence policies (including maternity leave, or attending to a sick child, and so on). While these are issues for all parents, they can become insurmountable for parents of children with disabilities who do not have the requisite support. Children with disabilities are typically more vulnerable to sickness. They may need operations or they may require appointments with medical specialists, such as physiotherapists, speech pathologists and other specialists. It is likely that their individual education plan will require ongoing scrutiny and frequent meetings with people in the school system (Freedman, Litchfield, Warfield, 1995; Irwin and Lero, 1997).

Typically, working parents manage these extra demands by taking unpaid leave, using up sick days and holiday time, making up time off from work later, and going to appointments after work hours if possible. Flexibility in the workplace that includes paid sick leave, personal days, and some flexibility in starting and ending work, including the opportunity to make up lost time, are considered essential for low-income single parents and especially single parents of children with disabilities. As the literature points out, however, low-income women have limited access to family-supportive workplaces that might provide these benefits (Piotrkowski and Kessler-Sklar, 1996).

Extraordinary Demands of Care

While the "welfare-to-work" literature has some relevance to the challenges faced by parents of children with special needs, and while the work/family literature is beginning to look at some of their issues directly, what seems to be missing from the literature is a comprehensive understanding of what is involved in caring for these children, and the challenges to maintaining paid work such care imposes. For example, while some of the literature acknowledges the inordinate amount of time it takes to organize and take children to appointments, such recognition does not go far enough. Nowhere in the literature is the parents' role as their children's advocate on all fronts acknowledged. Nor is there any awareness of the increasing need for parents to play this role in the face of cutbacks to basic services. Generally, everything that a parent must do for a normally developing child becomes more complicated when a child has a disability. The role of parent becomes more physically and emotionally demanding, and can take a huge toll on the parent and their capacity to remain in the workforce.

While the literature clearly outlines the extensive support needs of parents and their children, it also tells us that they are not able to access the supports they need. The need for quality and quantity of good, flexible respite care is still not being met (The Roeher Institute, 1999, Metropolitan Toronto District Health Council, 1997), and that need is expected to grow (The Caledon Institute, 1997). They also may have difficulty accessing support for leisure activities, (Perrin, 1989), appropriate health services (University of Western Ontario, 1993), and transportation (Bradley et al., 1992). Some families may have even greater difficulty

accessing services than others. For example, Hoare, Harris, Jackson and Kerley (1998) found that access to respite was determined by the type of disability and that respite was less accessible to families with low incomes and those who are visible minorities.

Indeed, if it is hard for parents in general to find supportive workplaces, then given the additional demands on the parent of a child with disabilities, the challenge of finding a workplace willing to accommodate these additional needs seems daunting. This becomes particularly true in a work environment where downsizing is the norm and work pressures keep expanding.

Wages and Benefits

Schellenberg and Ross (1997), in a report by the Canadian Council on Social Development entitled *Left Poor by the Market* looked at causes of poverty among families that have been participating in the labour market. They found that for these families poverty is caused by low wages, unemployment and periods of time spent outside the labour force. They suggest that Canadian families are being pressured to increase their financial self-reliance as governments cut back on social programs. However, their report challenges the common assumption that a family in which one adult is working full-time cannot be poor. They found that in many jobs wages are too low for full-time workers to support their families adequately. One full-time worker, earning a minimum yearly wage brings home only about 40% of the income necessary to raise the family out of poverty. This situation is worsening. Between 1976 and 1995, the salary of full-time, year-round workers earning minimum wages declined by 25 to 30% in almost every province.

Furthermore, the welfare-to-work literature recognizes that single mothers may hesitate to work because they would lose health care/dental and other benefits. Again, this loss is of particular significance to parents of children with disabilities who often have expenses that are not covered by provincial health care (Irwin and Lero, 1997). Researchers in this field recommend that these benefits be sustained for low-income earners and that the threshold for allowable earnings be raised while women are gaining work experience (Parker, 1994) or re-entry work skills. Extended health care plans are unlikely to be available in low paying jobs, including the retail and service sectors, and, therefore, medical expenses remain an issue for low-income parents with and without children with disabilities in most provinces, though recently some provinces have moved to address this issue.

Summary

While the literature is extensive regarding single parents on welfare, and increasingly so regarding women's transition from welfare to work, virtually nothing has been written on the particular barriers faced by women on welfare who have children with disabilities and who wish to participate in the workforce. Even the work/family literature is scant when it comes to addressing the issues faced by families of children with disabilities. Indeed there is no piece of literature that attempts to synthesize what different bodies of literature say, and to outline in a comprehensive fashion the implications for this particular group of parents. Canadian researchers have not even been able to determine what proportion of Canadian families on social assistance include children with disabilities[3]. This is a strong indicator of a need for national statistical instruments to collect this information, and for research to be conducted in this area. Without literature and data that specifically focuses on this group of parents, there is less chance that their needs will be recognized, let alone addressed.

As is evident in existing literature, parents of children with disabilities face significant challenges and barriers. They are not a

homogeneous group, but are variously positioned along lines of disability, race, age, sexual orientation, education, work history, marital status, income, geographic location and ethnicity. Therefore, a host of social circumstances must be considered in an examination of the barriers faced by parents, both in accessing employment if they deem this feasible, and in getting the services they need. These issues need to be recognized and addressed in social policy.

The obstacles for single parents on social assistance who have children with disabilities, by inference, seem formidable, especially considering the severity of cuts to social services across Canada in recent years. With growing negative public attitudes toward single parents and others on social assistance, the invisibility in research and policy of the circumstances of this group of parents is cause for concern. A concerted effort and a commitment to support them is needed by agencies and governments.

Without public understanding and adequate support, families on social assistance who have children with disabilities are vulnerable to a range of additional pressures and crises which can lead to a downward spiral which, in turn, will further entrench their poverty. It is in the best interests of families, communities and society that poor families of children with disabilities receive whatever support they need to live dignified and relatively independent lives.

Endnotes

[1] At the time workfare was prohibited under the Canada Assistance Plan (CAP).

[2] Ontario, Ministry of Community and Social Services (1988).

[3] In conversation, Dr. Donna Lero indicated that efforts to find out this information from the Ontario government were unsuccessful as well. Nor was it possible to derive this information from Statistics Canada data.

V.
POLICY AND LEGISLATIVE FRAMEWORK

Throughout the 1990s, there have been changes to government policies and programs that affect families on social assistance who have children with disabilities, particularly in Ontario and Alberta. These changes have occurred during a climate of substantial increases in child poverty rates and homelessness, a recession (in the early '90s), high unemployment rates, government cutbacks, and shortages of affordable housing.

This section reviews policy in Ontario, British Columbia and Alberta which have an impact on parents making transitions from social assistance to the paid labor force, and who have children with disabilities. When this research was conducted, all three provinces were engaged in substantial restructuring and changes in relevant policy sectors. Government approaches to restructuring have been similar in Alberta and Ontario, whereas British Columbia differs somewhat. In some areas it is too early to judge the effectiveness of these changes, or how they might affect families who have children with disabilities.

It was beyond the scope of this study to undertake an in-depth review of government policies and programs. Instead, government-issued communications on relevant programs and legislation were reviewed. In keeping with the objectives of the study — that is to identify those factors affecting families who have children with disabilities seeking labour force participation — the following areas were briefly reviewed in the three provinces where the study took place: social assistance, education, childcare, housing and services. Documents by and interviews with senior agency personnel in each province provided information on how these policies and programs appeared to be working in practice and what, from their perspectives, were the key issues. The information available differed between provinces, and it was not possible to embark on a thorough information-seeking initiative given the restraints of the project. Nor was it possible to carry out a full comparison among the three provinces. The reporting of an issue in only one province does not necessarily mean that it is not an issue in the other provinces.

What follows is a cursory exploration of current policy frameworks.

The Role of the Federal Government

Many of the changes and cutbacks experienced at the provincial level have been precipitated by the federal government's budget cuts, including those to transfer payments, the replacement of the Canada Assistance Plan (CAP) with the Canada Health and Social Transfer (CHST). The Canada Health and Social Transfer was introduced following the 1995 federal budget. It transferred responsibility for welfare, social services, post-secondary education and health care services to provinces and territories. Provinces and territories were given control over the design and delivery of these programs, while federal cash transfers were reduced. Formerly the federal government cost-shared welfare and

social services with provincial governments under the Canada Assistance Plan (Rioux and Bach, 1995).

The federal government has also withdrawn altogether from responsibility for social housing. The federal government has not to date played a leadership role in addressing key problems such as homelessness, unemployment, childcare, and child poverty. Indeed, the implementation of the CHST saw the end of the federal/provincial cost-shared funds that were used for supports such as childcare subsidies, among others. This has contributed to increased precariousness of childcare and other services.

The Childcare Advocacy Association of Canada has expressed its concern over the resulting trends:

> *Since the Canada Health and Social Transfer (CHST) replaced the Canada Assistance Plan (CAP) on 1 April 1996, there has been a move toward deregulation of childcare, increased privatization of services and the dismantling of training programs. CAP, while not specifically designed for childcare service provision, enabled the provinces to cost-share funds with the federal government which were used to support childcare subsidies. Under the CHST, we are seeing the increased fragility of childcare services (Childcare Advocacy Association of Canada, 1996)*

Increasing regionalization of government responsibility has been one response to the resulting budget cuts on the part of provincial and territorial governments. Regionalization is intended to democratize service delivery and reduce duplication and waste by putting decision making in the hands of regional and/or local boards. For example, regional health boards, which include representatives from communities, are intended to respond more appropriately to the needs of specific communities or regions (Council of Canadians with Disabilities, 1998). Because these changes are very recent ones, the actual impacts of regionalization on children with disabilities and their families are not yet well documented, though there has been concern that regionalization may compromise access to services and reduce their quality (Council of Canadians with Disabilities, 1998).

Programs like the Child Tax Benefit, a minimal attempt to address child poverty, have failed to support children on social assistance, including those with disabilities, in the three provinces discussed above because the agreement with the provinces allows them to claw back the benefit. This agreement has meant that the additional monies being spent by the federal government benefit barely one-third of poor Canadian families with children (National Council of Welfare, 1998). Ironically, the rate of child poverty in Ontario has increased since the introduction of the Child Tax Benefit (CTB) (Statistics Canada, 1999).

As has been argued by the National Council of Welfare (1998), the policy on the CTB amounts to discrimination based on family status and gender.[1] They suggest it may violate the U.N. Convention on the Elimination of all Forms of Discrimination Against Women as well as the U.N. Convention on the Rights of the Child. Mothers and their children form the largest group on welfare and the poverty rate of families headed by single mothers "is the highest rate for any family type year in and year out and is consistently many times higher than the poverty rate for couples with children." Due to high levels of family breakup, the number of poor families headed by single mothers under 65 has nearly doubled since 1980, while the number of poor two-parent families has changed little. According to the Council:

> *The facts of the matter are overwhelming. Single mothers and their children are the family type that is most in need of help from governments. Yet single-parent families on welfare get little or no additional income from the Canada Child Tax Benefit in most parts of Canada under the new system.*

Nor does the new system provide support to families on social assistance who are trying to make the transition to the labour force. Recipients who earn more than a small amount of money every month lose a dollar of welfare income for every dollar of earned income in most provinces. (In British Columbia they keep 25% of money earned.) They cannot be assured in every province that they will be able to retain medical benefits, dental care and prescription drugs if they return to work (National Council on Welfare, 1998, p. 15). As noted in the literature review, this is of particular importance to families who have children with disabilities, who are likely to depend on these benefits.

The length of time that single-parent families are depending on social assistance is increasing. Yet, with the exception of Quebec, governments have failed to put in place key programs (i.e., childcare) that would remove barriers to single mothers getting off social assistance.

The reinvestment strategy associated with the CTB, which transfers funds that would otherwise have gone to children on welfare to provincial governments to "reinvest" as they see fit, has been acknowledged by the National Council of Welfare to be a "novel approach to developing social policy in Canada." They also recognize that it has produced some model initiatives that could be replicated by other governments. At the same time, they remain concerned about the lack of accountability and the resulting patchwork of programs across the country (National Council on Welfare, 1998, p. 19). Critics have also expressed concern that the lack of accountability and lack of an independent audit mean that there is no way to make sure that provinces are using the reinvestment in ways that were intended. Are federal mon ies supplementing provincial funds for children on welfare, or replacing them? Without accountability measures, there is a risk that children in low-income families could receive even less support than in the past, depending on the discretion of provinces and territories.

According to the National Council of Welfare, Ontario plans to spend $100 million of its first $117 million in reinvestment money on a childcare supplement to cover a portion of the childcare costs of some families. The supplement will be up to $1020 a child for low-income working families with children under seven. The rest of the funds will go towards other programs including Healthy Babies, Healthy Children, a program for high-risk babies, and increased funding for Children's Aid Societies that have previously faced years of substantial cuts (National Council of Welfare, 1998, p.21).

Alberta has chosen to use its Investment funds of $13.7 million for a Child Health Benefit, which provides dental, optical and ambulance services and prescription and over-the counter drugs to children in low-income families. As noted above, this is a critical protection for families who have children with disabilities wanting to return to the labour force. The province invested $75 million in a Family Employment Tax Credit initiated in 1997 (National Council of Welfare, 1998, p.22).

As mentioned below British Columbia took the initiative in beginning a Family Bonus plan in 1997, adding the Earned Income Benefit in 1998. Both programs along with the Canada Child Tax Benefit are delivered in one cheque. The government has also expanded childcare, and introduced a program that provides children with basic dental and eye care. These programs have cost millions of dollars, and as the National Council of Welfare points out, the federal investment of $63.8 million is minimal compared to provincial expenditures (National Council of Welfare, 1998, p.22).

National Children's Agenda

The federal government has initiated a project called the "National Children's

Agenda" which has been described as a collaborative effort between federal/provincial/territorial governments. The Federal-Provincial-Territorial Council on Social Policy Renewal is co-ordinating the effort among governments and with Canadians to develop new cooperative approaches for addressing children's needs through a National Children's Agenda with a shared vision for Canada's children. The purpose of a National Children's Agenda (NCA) will be to ensure that all Canadian children have the best possible opportunity to realize their full potential. The Agenda will support the critical and primary role that parents, families and communities play in the lives of children.

The federal government has committed $2.2 billion in new funds for early childhood, which the provinces will use at their discretion. The NCA and the budget that will accompany it are still in the planning stage. It is unclear how much it will ultimately cost and what it will entail. As yet it could include a broad agenda including everything from longer stays in hospital for new mothers, through early education and childcare programs, to tax benefits to families with children to housing.

It is particularly unclear as to what it will mean for children on social assistance, or children with disabilities. Hopefully the goal "to ensure that all Canadian children have the best possible opportunity to realize their full potential" will mean that children with disabilities will benefit as well. However, it is worth noting that children were barely mentioned in the most recent federal budget.

Ontario

Income Assistance

In 1995 the Ontario Provincial Government passed the Social Assistance Reform Act, which substantively altered social assistance legislation and indicated a dramatic departure from previous legislation, policies and procedures. In 1997, this piece of legislation was replaced by the Ontario Disability Support Program Act, which covers support for adults and children with disabilities; and the Ontario Works Act, which applies to all other recipients of social assistance, including families who have children with disabilities. Single parents have been transferred from the old Family Benefits Program to Ontario Works, the government's mandatory work for welfare program.

Under the Ontario Disability Support Program Act income support for disabled adults has been separated from social assistance for non-disabled adults. This program along with the subsidy for children with disabilities (i.e. Assistance for Children with Severe Disabilities) continues to be administered by the provincial government. Other social assistance programs have been downloaded to the municipalities, and the proportion paid by the province for these programs substantially reduced.

While single parents with school-aged children are expected to work under new Ontario Works legislation, such a requirement may be "deferred" for people where participation is "impractical," such as where a school-aged child is not attending school, or a family member requires extensive physical care. How "impractical" is defined, however, appears to be at the discretion of the caseworker.

Critics have charged that changes to social assistance legislation are unnecessarily punitive. Indeed under the new legislation neighbours of social assistance recipients can be charged if they fail to co-operate in providing information to fraud investigators. Welfare recipients living in rental accommodations costing more than their shelter allowance (which particularly in the urban areas is far from adequate) can be cut off welfare simply because they paid their rent. In such cases the assumption is that they must have cheated to do so. Single

parents trying to establish a new relationship are no longer allowed a three-year window to stabilize and ensure the relationship will be long-term. It is expected that a live-in partner of the opposite sex should take financial responsibility for a single parent and her children immediately[2]. Workers are instructed to consider things like whether a "boarder" pays for pizza or helps the children with their homework to determine whether a relationship is conjugal. The result is that genuine boarders taken on out of financial necessity must tolerate the scrutiny of caseworkers. However, this "spouse in the house" rule has recently (June 29, 2000) been declared unconstitutional by an Ontario court. The Premier has announced plans to appeal the decision.

Under new rules there are no appeals regarding discretionary funding. An election promise to subject welfare recipients to drug testing has also been criticized as unnecessarily punitive and demeaning, and may even be in violation of human rights. Most recently the Ontario government has proceeded to implement a requirement that stipulates that those receiving social assistance who own their own homes must put a lien against the property. In the event the house is sold all monies received must be repaid from the sale of the house, even if the money was earned under workfare. This has particularly serious implications for those in rural communities where the value of the house is likely to be modest, and obtaining rental accommodation problematic. It will likely deter people from moving to obtain employment.

It should also be noted that under changes to OSAP regulations, single parents wishing to return to school at the post-secondary level, will no longer be able to remain on social assistance but will be supported under the student loan program. This will mean that this group of parents will have to take on a substantial debt load in order to complete their education.

Childcare[3]

Responding to changing workforce participation rates by parents, particularly mothers with young children, growing child poverty rates, and research indicating the benefits of quality early education programs for children, each consecutive Ontario government has increased its funding commitment to childcare. Each new investment was aimed at enhancing the quality and accessibility to childcare. According to the Ontario Coalition for Better Childcare, Ontario leads the provinces in the percentage of children served in regulated childcare settings.[4]

However, as the Coalition points out, the current government has been reducing funding and standards for childcare. This included cuts to programs that assist childcare programs to integrate children with disabilities. It also involved cancellations of pilot projects, planned childcare centres and new junior kindergarten programs,[5] reduced funding to existing junior kindergartens and childcare resource centres, reductions in subsidies, elimination of the Program Development Fund, elimination of pay equity (before a court ruled that it be reinstated) and cancellation of the conversion program for commercial childcare.

According to the coalition, the downloading of childcare funding onto municipalities has increased the municipal funding commitment by 400%. While municipalities were ordered to maintain 1997 service levels, they were also provided with a "tool kit" to help deal with extra costs including a promise to reduce standards and the option of funding unregulated care arrangements. While the coalition acknowledges that mandating childcare at the municipal level is a positive step, they have expressed concern that inadequate funding together with encouragement to opt for informal care will result in the collapse of regulated childcare.

In terms of Ontario Works the coalition has expressed concern regarding the implications of quality of childcare for children of

participants:

> *Amendments to Day Nursery Regulations accompanying the legislation make it possible, for the first time to fund unregulated childcare under the DNA. This provision includes care for the children of parents required to participate in Ontario Works.*

Twelve thousand childcare "placements" have been attached to the program. The amendments do not specify the age of the child, and a companion piece to the Bill indicates that parents with children in kindergarten will be included. Funding for Ontario Works childcare comes out of the current childcare budget. It pays a maximum of $16/day whether the child requires full- or part-time care. The placement does not have to be in a regulated program. Some municipalities have indicated that they will use only unregulated care for the children of Ontario Works participants. This is a first in Ontario where public policy determines that the children of welfare recipients will be limited to substandard care (Ontario Coalition for Better Childcare, 1997).

Under Ontario Works legislation, if a child is in regulated childcare, providing a subsidized space is available, the province will pay the entire cost. However, if the child is in informal care, the province will pay to a maximum of $407 per month. Reduced funding for programs assisting childcare centres to integrate children with disabilities, reduced subsidized spaces, together with the likelihood that municipalities will opt for informal care has serious implications for parents who have children with disabilities wishing to participate in Ontario Works. For parents who must hire someone to come into the home to look after their children with disabilities, $407 will not go very far.

More recently the Ontario government has eliminated subsidized childcare for parents with liquid assets greater than $5000. This will mean parents with lower incomes may have to liquidate assets in order to pay for childcare, therefore preventing them from saving for both their children's future (e.g., their education) and their own. This has serious implications for all children, particularly those with disabilities, whose financial futures are often precarious.

Housing

Subsequent to the decision of the federal government to withdraw financial support for public housing, the Ontario Government followed suit, cancelling "pages" of planned co-operative housing, and downloading responsibility for existing public housing to the municipalities. At the same time, they removed rent controls on vacated apartments allowing landlords to raise the rent to whatever the market would bear. The result has been a crisis in housing, especially in urban areas such as Toronto, with homelessness particularly among families with children, rising to unprecedented levels. The province responded to a report on homelessness undertaken by Golden (1999), committing $100 million to housing. To date, however, only a third of this amount has been spent. The City of Toronto has also taken concerted steps to address the problem. The Federal government has announced a commitment of $756 million to homelessness. While it is encouraging that there have finally been some signs of action at all three levels of government, none of these initiatives appear to address the lack of affordable housing for low-income Canadians.

Housing is a particular issue for low-income parents who have children with disabilities, where accessibility may be a factor along with problems housing children with behavioral problems.

Education

Under new legislation, the government has dramatically changed the way education is

run in Ontario. School boards have been amalgamated and their autonomy and power reduced. Education is now completely funded and, for the most part, controlled by the province.

Funding formulas, including Special Education, have been completely overhauled. Under a new funding formula, each school board is required to submit applications for Intensive Support Amount (ISA) funding for each child with a disability. School boards criticize the application process for being intensive and time consuming. It requires additional testing and extensive documentation that takes staff away from the children they are meant to serve for a considerable block of time (at least 5 weeks). Parents are very concerned that the model is medically based, with the result that children are labelled in predominantly negative terms in order to meet funding criteria. Now report cards must also reflect the emphasis on weaknesses rather than strengths, to the dismay of parents and children. As well, urban school boards (e.g., Toronto and Ottawa) insist that the funding formula does not take into account the disproportionate number of children with disabilities in urban centres.

Although some boards are apparently satisfied and better off with the new funding formula, there is great concern among parents and educators in other boards that the new funding formula will ultimately result in a drastic decrease in resources for children with disabilities. A promise by the provincial government of an additional $40 million is considered by most to be inadequate.

Services

It is beyond the scope of this study to give a full accounting of what has happened to services for children with disabilities in Ontario. Nonetheless, it is safe to say that cutbacks to the medical system, agencies, and services, in general, have had a direct and serious impact on children with disabilities.

Some services are delivered through regional Community Care Access Centres (CCACs), funded through the Ministry of Health. There are 43 CCACs throughout Ontario. CCACs arrange health and personal support services in people's homes and for children in schools. They provide information and referrals to community services. In-home services provided through Community Care Access Centres include: nursing care, physiotherapy, occupational therapy, speech and language therapy, palliative care, dietetic services; social work, personal support services, such as bathing and dressing, meal preparation and feeding; and homemaking services, such as cleaning and doing the laundry. There is a limit of 15 hours a week for services from the centres, under normal circumstances. Previous to the current government, there was no limit in hours. Instead, numbers of hours of services was based on need.

Services are also offered through the Ministry of Community and Social Services (MCSS). In-home and out-of-home respite are funded by MCSS and delivered through community agencies, or parents themselves arrange for such services. Two programs for families who have children with disabilities are delivered directly through the Ministry of Community and Social Services. These are Special Services at Home and Assistance for Children with Severe Disabilities (Formerly the Handicapped Children's Benefit).

Special Services at Home (SSAH) provides support to families caring for children with physical and/or intellectual disabilities. Services related to personal development and growth, and/or family relief and support are funded by the program. Families can access SSAH only if the services are not available through other community services.

Extraordinary expenses, such as food, clothing, or equipment may be funded through Assistance for Children with Severe Disabili-

ties. The former program assists parents with disability-related costs such as travelling to doctors and hospitals, special shoes and clothing, parent relief, wheelchair repairs, and hearing aid batteries. Financial assistance ranges from $25.00 to $375.00 per month, depending on need and a means test. Financial assistance is also available for basic dental care, drugs, eyeglasses, and hearing aids. Equipment is funded by the Assistive Devices Program, and diapers are provided through a program managed by Easter Seals.

The government has undertaken a number of initiatives aimed at reforming, restructuring, co-ordinating and/or integrating services, and making them more effective and accessible. For example, MCSS has undertaken an initiative called "Making Services Work for People" which engaged agencies, communities, and individuals across the province and set out a new framework for services for children and adults with developmental disabilities. The government has committed itself to a "local system of services" subject to provincial requirements, where families will be able to access more easily and earlier "a consistent range of services." The government has stated that the changes will mean that "people who are most in need will receive essential support."

Such features of "Making Services Work for People" such as reducing the number of "access points," integrated and co-ordinated assessments, and so on, are likely to be well received by users. However, language such as "most in need" and "essential support" seem aimed to reduce costs by redefining need so that more and more children and adults with disabilities are ineligible for services, and the services available are minimal. Many parents have expressed concern about the new Individualized Supports Agreement (ISA) that will determine what services and supports they receive.

Furthermore, the government has promised to make the changes with "existing resources." It is yet unclear what these services will look like and who, in fact, will be served. For example, the government has stipulated that "each local system of services *must increase the level of resources* used for early intervention and developmental supports for:

- children under six years of age with developmental delays
- children under six years of age with aggressive behavior, or in the early stage of developing an emotional or behavioral disorder; and
- adults with developmental disabilities who need support to help them live independently (Ontario Ministry of Community and Social Services, 1997, p. 21)

The goals of early intervention and supported independence are laudable goals. But there appears to be a gap in services for children aged six to 18. There seems to be an assumption on the part of government that this group is well served and not in need of additional services, but most parents find that there is a steady of erosion of services for this age group. There is a risk that if the increase of resources mentioned above is to be achieved with "existing resources," new priorities could be met at the expense of further erosion of services for children six to 18.

It should be noted that for services where the government has apparently introduced more funds, the result is not necessarily more services for the individual family. For example, in the spring of 1999 the government announced an additional $10 million for respite care for parents of children with intellectual disabilities. However, in actual fact, most parents receiving funds from this program (SSAH) have seen their monthly support reduced as part of an "equity" plan. As other

programs are cut, more and more families are forced to depend on services such as SSAH, resulting in less support for everyone.

The Ontario government commissioned a study of Children's Treatment Centres (ARA Consulting Group, July 1999) across the province. The report, *Role Review of Children's Treatment Centres, Final Fact Finding Report,* identified a number of issues (p. 70):

- The service system is a patchwork of program providers, eligibility criteria, and so on, with gaps, inconsistencies and little co-ordination.
- Although some Children's Treatment Centres (CTCs) have internal case managers, no one is accountable for case management for the child/parent across the system of services. The role of case management usually falls to the parent(s).
- There is insufficient integration between ministries at the policy and local delivery levels, creating unnecessary gaps, duplication and confusion.
- Data gathering within the CTC's and among all service providers is not comprehensive or consistent, and there is no common up-to-date information system in place to support effective monitoring or management of needs and services.
- The meaning and management of waiting lists vary among CTCs, but parents report significant delays in receiving many services.
- All school-age responsibility for speech language therapy is divided between school boards (for 'language' therapy) and the school health provider (for 'speech' therapy).
- The requirement for a physician referral to access CTC services is often a barrier.
- In many communities the competitive model used to contract local agencies to provide service results in further fragmentation of service provision, and a decrease in service quality and continuity.
- There is concern and debate about the [trend to] use consultation therapies as a means to manage limited resources [and whether as a result children's needs are being adequately met]. They also point out that this approach often results in an unrealistic expectation that the parent will provide the therapies.
- Although many CTCs aim to be family centred they are not generally perceived or experienced that way by families. Many of the funding, accountability, organizational, and service delivery models are not aligned to meet family needs and expectation.
- In addition to individual community issues, some consistent gaps in service were noted across the province (i.e., all types of respite services, teen services, transitional supports for teenagers moving into adulthood, psychology and behavior management).

There are substantial discrepancies across the province in terms of how much money is spent in a particular area and general availability of specific services. This is particularly true in areas where there has been significant population growth, but funding of services has not kept pace. For example, according to figures compiled by Durham Region, in 1997-98 the provincial community and social services ministry spent $186 per child in the Durham Region, $356 per child in Toronto, and $477 per child in North Bay. Families may face long waiting lists for treatment services (e.g., occupational therapy) in one part of the province, and not in another. Some parts of the province have no rehabilitative services at all.

Following a series of inquests, steps have been taken by the Ontario government to systematically reform the child welfare system, including major changes to the *Child and Family Services Act.*

British Columbia

Social Assistance

British Columbia introduced changes to its social assistance program in 1996, replacing the GAIN Act with British Columbia Benefits and initiating the Disability Benefits Program. Although not as dramatic as changes in Ontario and Alberta, the changes in British Columbia have nonetheless emphasized cost savings and stricter enforcement. Although social assistance rates for families were not reduced, single people and childless couples faced significant reductions. As well, British Columbia has eliminated a policy that allowed social assistance recipients to earn a flat amount before it affected the social assistance benefit. Now all earnings result in a corresponding and immediate cut of 75% of the earnings.

While no mandatory work program has been introduced, recipients are required to look for work or participate in the employability programs. All parents are encouraged to look for work, and those whose youngest child is over seven can be denied benefits for failing to do so. Certain categories of recipients (e.g., parents with a disabled child) may be "temporarily excused" from this requirement, subject to the discretion of the worker.

To its credit, British Columbia led the way in being the first province to introduce a Family Bonus — a direct payment to low- and modest-income working families with children. Since its implementation in 1996, the Federal Government has followed suit with the Canada Child Tax Benefit. Although the Family Bonus has been credited with reducing the poverty gap (the amount of income that is needed by families below the poverty level to take them out of poverty) by 19%, it did not actually increase the amount of money received by families on welfare. Nonetheless, it has been credited with contributing to a reduction in the number of children and families dependent on welfare because it has reduced some of the disincentives to work through ensuring that working families with low incomes are not worse off than those on social assistance (Mendelson, 1997).

The British Columbia government has also introduced a new program called the British Columbia Earned Income Benefit that directly benefits families with earned income of more than $3,750 in the previous year. The benefit also subsidizes medical, dental, and pharmaceutical costs. The amount decreases after a family's annual income passes $20,921. As well, the government provides some assistance with transitional costs involved in moving from social assistance to work (e.g., clothing, transportation, childcare).

Childcare[6]

> *Childcare is fundamental to the health and well-being of our society. Parents, children, communities –everyone benefits from a child-care system where every child regardless of ability, is welcomed and included.*
>
> *— Lois Boone, Minister for Children and Families*

Childcare has seen some positive developments over the last several years, with the number of spaces in regulated care substantially increased. Subsidies are available for a range of childcare options, including in-home care and other informal kinds of care. Parents may direct the subsidy to the childcare arrangement of their choice. Beginning in 2001 children from kindergarten through age 12 will have access to before- and after-school care at $7/day.

British Columbia is in transition from the previous "Special Needs Day Care Program" to "Supported Childcare." With the introduction of "Supported Childcare," the province has taken a major step forward in ensuring integration and equitable access for children with special needs. Whereas under the old program, parents had few options and were largely restricted to a "specialized"

child-care setting, which was often not close to home or work. Under the new program, the parent chooses the childcare setting for their child. The parent is then involved in determining what additional support the child needs. The parent also helps to determine which professional services — for example, speech and physical therapy, nursing care — are required while the child is in childcare.

Parents still pay the same basic childcare space fee as parents with children who do not need extra support. Low-income parents may apply for a childcare subsidy to help cover the basic fee. The amount of the subsidy is based on family net income as well as the number of people in the family. There is a maximum allowed, and the parent must pay childcare fees exceeding the subsidy amount.

However, while under the old system, childcare and related services for children with disabilities were funded entirely by the government regardless of family income, parents must now submit to a means test both for the regular fees *and* the additional costs of special supports for the child. Affordability is likely to be a key issue for parents of children with special needs requiring childcare.

Childcare along with social assistance has recently been moved from one ministry to a new ministry — Ministry of Social Development and Economic Security. According to Diane Luscombe of West Coast Childcare Resource Centre, childcare is now in "limbo" as it is unclear what the implications of this move are. There is some concern that there will be a return to seeing childcare as a social program, as opposed to a universal one. Others are hopeful that, nonetheless, the emphasis will remain on early child development. In terms of the new "Supported Childcare," Luscombe anticipates it will take three to five years before it is fully implemented across the province and can be properly evaluated.

Housing

The provincial agency responsible for managing, developing and administering social housing is British Columbia Housing. They are responsible for over 37,000 social housing units across the province and have funded more than 6,500 units of affordable housing since 1994. High rents and homelessness are a problem in British Columbia, as in other parts of the country. However, unlike most provinces, British Columbia continues to fund new social housing through a comprehensive program called the HOMES British Columbia program.

Families make up 63% of those who use social housing in British Columbia. Statistics were not available as to how many of these families have children with disabilities. However, according to the British Columbia Housing website, only 1% of all social housing households (including those for seniors and disabled adults) require wheelchair modified housing.

Education

Special education policy in British Columbia was revised in 1994 as a result of a review of special education programs and services undertaken by the Ministry of Education. The Ministry places high priority on inclusion issues, requiring integrated placement "unless the educational needs of the student with special needs or other students indicate that the educational program for the student with special needs should be provided otherwise" (Ministry of Education, 1995). Despite this allowance for exclusion, full inclusion is seen as the first and optimal choice, and neighbourhood school classroom teachers are required to adapt instruction and evaluation methods and materials as necessary. Placement in other settings is considered appropriate only after the school board has made all reasonable efforts to integrate the student. In addition such placement is regularly

reviewed and updated and intended to lead to full inclusion in neighbourhood school classrooms as soon as it is feasible. Identified students with special needs must have Individual Education Plans (IEPs) that are reviewed annually and include parent input. Students are assigned case managers to coordinate the development, documentation and implementation of their IEPs.

Vancouver has led the way nationwide in its efforts to fully integrate children with disabilities into the regular classroom, but there is worry that these efforts are being put in jeopardy, because there is insufficient funding to provide the necessary supports. The average funding for each British Columbia student was $7,142 in the 1997–98 school year. For those with disabilities, supplemental funding ranged from $350 to $32,975, depending on need (British Columbia Ministry of Education, 1999). Changes in levels of funding to the educational system have posed a grave concern to those concerned about supports to children with disabilities.

Special education in British Columbia is currently under review. The Ministry has a web page dedicated to the Special Education Review, with submissions from individuals and organizations, outlining the ways the system works and how it can be improved. While the results of the review are not yet available, these submissions outline some critiques of the system. Organizations such as the Autism Society, the British Columbia Association for Community Living and the British Columbia Council for Exceptional Children have responded with mixed reports. On the one hand, they give positive reports of some aspects of the system. The British Columbia Council for Exceptional Children felt that the Ministry has shown clear commitment to provide an inclusive educational environment, and reported that, whenever possible, students are integrated with their age-appropriate peers. They felt that the system has many strengths, including the wide variety of support models for inclusion, collaborative use of IEPs to plan, develop and implement a student's program in all areas of development, and evident collaboration among teachers, administrators and district support personnel. The Autism Society reported that the system provides elements of inclusion, such as the provision of Speech Language Pathologists, who are highly beneficial to the successful education of children with autism.

These organizations also felt that the system could be significantly improved, and were worried that reductions in special education budgets in school boards around the province put the elements that are working at risk. The following critiques represent a sampling of comments from submissions by these organizations. They do not provide a comprehensive review of the system:

- inconsistent standards of special education services around the province
- a lack of accountability and/or a shifting mandate for services
- a lack of training among staff
- poor or inadequate use of Individual Education Plans
- a lack of parental involvement
- negative attitudes as problems
- delayed support provision resulting from delays in identification and assessment of students
- restrictive eligibility criteria to qualify for services
- inadequate support for some students
- insufficient emphasis on early intervention
- insufficient access to health services funding through the Ministry of Education, including speech/language pathology, physiotherapy, occupational therapy, behavioural services and counselling.

Services

Services for children in British Columbia are provided through the recently formed Ministry for Children and Families. British Columbia has established a Children's Commissioner to ensure: that there are proper services in place for all children, that the Ministry for Children and Families provides services, and that families have someone to talk to if the services are not in place according to the Children's Commission Act.

The Services for Children and Youth with Special Needs and their Families branch provides services to support community inclusion of children and youth with disabilities and their families. Services are intended to allow parents as much choice as possible, under the British Columbia Benefits (Childcare) Act and the Child, Family and Community Service Act. Programs and services fall into two categories: developmental and support.

A range of services specific to children with disabilities and their families are provided through Developmental Services for Children and Youth with Special Needs. Some of these are offered in the home, such as Infant Development, Early Intervention services (physiotherapy, occupational therapy, speech and language therapy and family support), and Behavioural Support for Children with Autism. Supports in childcare and at school are also offered by the Ministry through Supported Childcare and School-Aged Therapy Services, which provides school-based occupational therapy and physical therapy.

Support Services focus on home and community supports for children and families. Services in this category include:

- The At-Home Program, which provides respite and/or medical benefits
- Respite Services
- Associate Family Services (partnership between a trained family and birth parents to provide care in the trained-family home).
- Nursing Support Services
- Children and Youth Care Workers for help with child management and/or parenting skills and assistance for the child's development of social, life and other skills.
- Homemaker/Home Support Workers
- Parent Support for Families (support groups, parent-skills training, counselling, life skills and organized activities).
- The Professional Support for Children with Special Needs Program (promotes community integration opportunities).

Public Health and Family Support Services

Public Health programs and services aim to maintain and enhance the health and well-being of children, youth and families.

The Ministry for Children and Families has long-term promotion, prevention and early support strategy goals that increase resiliency and capacity of children, youth and families, engage community support and promote a family-supportive, child-centred service delivery system. The Ministry provides services that families on social assistance can access that are not necessarily disability-specific. Services are jointly funded by the Ministry for Children and Families, the Ministry of Health and the Ministry Responsible for Seniors under policy provided by the Child and Family Section, Ministry for Children and Families. Supports to children and families, such as public health nursing, nutrition, dental, hearing, speech/language, mental health and school-based services are delivered by regional health authorities on behalf of the ministry.

A 1998 report by British Columbia's Office

of the Child and Youth Family Advocate found that "children and youth report significant barriers to service, which the government must improve, if not eliminate." The report claimed that services to children and youth had not improved since 1995 because the Ministry is focusing too much on administrative restructuring and not enough on direct services. In particular, the report stipulated that the government should produce a " needs-based budget to address the inadequate resources for essential services to assist children and youth with visible and invisible disabilities, drug and alcohol problems, and mental health problems."

The Office of the Child and Youth Family Advocate developed a Barriers to Service Framework, based on the principles of good service delivery: accessibility; responsiveness and timeliness; inclusiveness; focus on best interest and solution-based planning; comprehensiveness; and accountability. This included barriers experienced by young people with disabilities, among other young people. Based on 4,633 requests for assistance from young people, and from adults concerned about young people, 28 barriers were identified and grouped. The following kinds of barriers were most frequently cited, and refer to the whole range of services, from disability-specific to information about safer sex , drugs or alcohol or other concerns of youth:

- Inability to find needed information and gain access to limited resources
- Lack of response
- Individual not treated respectfully, individual's views not sought.
- Plan not reflecting what individual wanted; individual not accepting of plan
- Services offered not reflecting individual's wants/needs

Alberta

Social Assistance

In March 1993, the Alberta government led the way in announcing major changes to its welfare system and introduced a new general social assistance program called "Support for Independence" (SFI). The changes were meant to transform what was considered a "passive" assistance program to "an active employment and training initiative." Described in government documents as "a program of last resort that actively promotes self-reliance and financial independence through employment and family responsibility," it is intended to provide financial security for people who cannot work, and temporary assistance to those in need. The stated goal is to help people become more independent through providing training and education, creating jobs through partnerships with employers and communities, and helping recipients find jobs.

But, as is so often the case, stated government goals are not necessarily reflected in practice or outcomes. According to a study of food-bank usage undertaken by the Edmonton Social Planning Council, the current government SFI Policy:

> *Appears to make recipients more dependent and for longer. Recipients are receiving no support to help them find work. They receive no resources to photocopy resumes, get appropriate clothing for job interviews, buy a bus pass to get to the interview, or even a telephone to find out if they got the job. This lack of direct employment support locks recipients into a longer-term stay on SFI, at benefit levels inadequate to meet basic necessities (Foster, 1999).*

The apparent priority of SFI officials to reduce the caseload by moving clients into training and employment was not borne out by the Council's study. Among a sample of those clients (10%) whose cases had been closed in the last three years, only 10% held full employment while 44% had no source

of income whatsoever. According to the Planning Council, it is not unusual for families to be cut off social assistance without any alternative income.

Furthermore, while welfare rolls have dropped, the reduction matches the increases to the number of individuals receiving Alberta Assistance for the Severely Handicapped. Some critics have suggested that people may merely be moving off of one assistance program onto another.

When it comes to what is required of families on social assistance, Alberta's rules are among the strictest in the country. Mothers with newborn babies are expected to return to work when the child is six months old (compared to school age in Ontario, or seven years of age in British Columbia). That welfare rates are inadequate for families is indicated by the widespread and increasing usage of food banks. As is the case elsewhere in the country, children comprise the largest group of food bank users (over 40%), and frequently go hungry. Parents often go without food themselves to ensure there is more food for their children. In families where the parent has completed work training but has failed to find a job, the family may nonetheless have their welfare benefits terminated.

Families in "special circumstances," that is, caring for a disabled family member, or who have unusual "difficulty in coping with the competing demands of work and family," or who have recently left an abusive situation and require a period to readjust, may be defined as "unavailable" for work or training. However, according to agencies who support families who have children with disabilities,[7] workers do not always allow or make clients aware of these exemptions, with the result that these families may in practice be treated the same as families who do not have children with disabilities. An example was given by one professional who described the situation of a single mother with two preschool children, one with Down Syndrome as well as serious medical fragility. Despite the fact that the cost of providing subsidized supported childcare for both children would far exceed the modest $1,200 a month this mother was receiving in social assistance, welfare decided she had to return to work. The mother was reluctant to do so because of previous attempts at childcare where her child with medical problems had ended in up in hospital emergency. Only after strong intervention on her behalf by another agency was she finally allowed to stay at home.

According to one agency for children with disabilities, social assistance intake workers are generally not very helpful to parents of children with disabilities, for example, neglecting to tell them that they are eligible for additional funds.

There is one important change to the social assistance system that may benefit parents who wish to move into the workforce. Certain health benefits, such as dental care are linked to Social Assistance. In the past, some people were reluctant to give up welfare to enter employment because they would lose these benefits. Alberta now allows people newly entering the workforce to retain benefits for a short term. This is expected to ease the transition to the labour force. However, after a few months, individuals lose this coverage and must rely on employment benefits, or pay for such services themselves. Unfortunately, in the types of employment gained by many people coming off social assistance, health benefits are not available, and the wages are low. So this arrangement continues to be a barrier in the long term, especially for parents whose children may have higher than usual health costs.[8]

The government is considering changes to its Assured Income for the Severely Handicapped (AISH) and Assured Support (income support for disabled adults), taking into account the understanding that there are varying degrees of disability that can be

permanent, temporary, or episodic. There is discussion of making the program more flexible and supportive of those who are disabled but wish to work. At the moment, Alberta is unique in that there is no limit on the assets a person with a disability can own (only income is considered), before receiving AISH, but this has been the object of recent discussion as well and may soon be changed.

Housing

Responsibility for Housing in Alberta has recently been transferred from Housing and Consumer Affairs to the newly formed department of Alberta Community Development. It is unclear whether the new department will continue to carry the programs offered through the former Ministry, or develop new or altered programs. The programs described below are currently in use and have been carried over from the old department.

Low-income families, and families that include people who use wheelchairs are among the groups that may be eligible for the Community Housing Program or the Private Non-Profit Housing Program. Through these programs, families may be offered a space in a housing project or co-op in which rent is based on 30% of the household's adjusted income. Applicants are given priority based on need, as determined by income, assets and their current housing condition. Costs are shared by Canada Mortgage and Housing Corporation (CMHC) and Alberta Municipal Affairs. However, no new funding is available for either program.

The Rent Supplement Program subsidizes rents in eligible private sector rental projects. Eligibility is determined by need, similar to the Community Housing Program. In this program, Alberta Municipal Affairs and CMHC pay private landlords a rent supplement to subsidize the rent of people with low incomes.

A similar project is the Rural and Native Housing Program. This program provides rental homes and apartments at 30% of a family's gross income to low-income families in small rural communities. This program is available only to families (at least one parent and child), seniors, and persons with disabilities in need of improved housing with an annual income within established maximum income limits. Although the program claims to prioritize people most in need, families who live in extreme poverty may have difficulty accessing it, since to qualify, the family must have a good credit rating and be able to make rental payments. Like the other subsidized housing programs, no new funding is available, so availability depends on vacancies in the current portfolio of spaces.

Another program that families may be able to access is the Home Adaptation Program, which assists with the costs of modifying people's homes, or building new housing to accommodate people who use wheelchairs. It is available to both homeowners and tenants, if they have an annual income under $30,000. Assistance comes in the form of a grant of up to $5,000.

Social housing in Alberta virtually ground to a halt in 1993 with the elimination of the Federal deep subsidy program. While buildings built before 1993 continue to be funded by the federal government (and will be for the duration of the mortgage) no new building has taken place. Housing advocates are concerned not only that available public housing falls far short of the need, but also that when the mortgages come to an end there will be no funds to maintain and repair the aging buildings. As a result, there are long waiting lists for subsidized housing in the province. For example, in the City of Edmonton, there are approximately 35 family-subsidized homes that are adapted and are wheelchair accessible. There are 150 families on a waiting list.

Childcare[9]

All services for children including childcare have been recently subjected to restructuring. New guidelines regarding childcare and implementation by a local authority allows for greater flexibility across the province. However, the installation of local authorities has also meant there are inconsistencies across the province in terms of how regulations are interpreted, a lowering of standards, and an increase in unregulated care. One childcare expert commented that, in Edmonton if you have more than four dogs you have to have a kennel licence. But, due to a decision by the provincial government four years ago, anyone can look after six children in their home without a licence.This is because with the new guidelines, regions had to agree to not change standards for one year. More regulation is likely to occur in coming years.

The concept of integrated childcare is supported from a policy standpoint. For example, the policy manual for Day Care Services, Edmonton Region, entitled, *Integrated Day Care: Regional Guidelines,* states a strong philosophy of inclusion:

> *to provide an inclusive childcare environment for children with special needs in their own community...children with special needs should have access to the same types of experiences as children without special needs, but may require extra support in order to be included with their peers. (p. 2)*

However, what was formerly a large document on "Integrated Childcare Guidelines" has been replaced by a document a few pages in length.

Furthermore, there is nothing in place that says a particular childcare centre has to accept a child with a disability. While some childcare centres readily accept these children with or without additional support, others refuse them admittance despite the fact that to do so is legally tenuous. (Unfortunately, those who do accept children with disabilities are not always those with standards above the provincial minimum.) Furthermore, children whose parents are not working may not be eligible, funds may be 'not available,' and programs that wish to accept children with disabilities may be declined funding. Segregated settings for children with disabilities in Edmonton have increased in the last few years. An increase was also seen in Calgary this year when Alberta Children's Hospital cancelled a mobile team which provided community-based therapies in childcare centers. As a result, many children went to segregated programs.

Asked to comment on the accessibility of childcare for children with disabilities in Alberta, the Executive Director of a service agency in Edmonton described a recent instance dealt with by her staff. One of her staff recently spent an entire day dealing with a centre that had refused to accept a disabled four-year-old child without a "key" worker. The mother was trying to attend a school that would not allow more than three days of absence. The centre was one of a group of centres that had previously met municipally set standards that were higher than the province's, and required that the centre meet the needs of children with disabilities. The centre received additional funding from the municipality to meet these standards. With funding cuts, these standards are no longer adhered to or enforced.

Some community services support inclusion of children with disabilities in childcare through helping with physical supports, providing staff training, helping them find other resources, and, in some cases, providing child/worker ratio enhancement. Parents who have children with disabilities and who meet income requirements are eligible for subsidized childcare. Parents on social assistance can receive funding for Handicapped Children's Services for early childhood education.

As parents on social assistance are required to return to work when their baby is six

months old, according to one childcare professional, parents moving from social assistance to low-paying jobs are forced to seek low-standard unregulated care for their babies. Government subsidies (about $400 per month) do not cover the higher cost of quality infant care (average cost is $700 per month).

As is the case with most other provinces, there is no regulated childcare for children older than 12, including children with developmental or physical disabilities who may still require it. This is a serious problem for parents of these children who need to work.

Services

The program in Alberta that provides support to eligible families who have a child with a disability is Handicapped Children's Services (HCS). HCS does not provide actual services to families. Rather, the program offers funding, information and referrals to help families access community supports, such as support groups, relief services and programs; services are delivered by third parties.

Handicapped Children's services also provide funding for "extraordinary costs" of caring for a child with a disability. They help cover the expenses of family support such as sibling care, relief and homemaker services, travel, meal and lodging expenses when accessing treatment or specialized services away from home, authorized dental/orthodontic treatment, prescription drugs and ambulance services, prescribed special formula or diet, psychological services, day care aide support, child's clothing (under exceptional circumstances) and out-of-home placements.

However, while support through Handicapped Children's Services is available, not all parents who need it have access to it. Critics suggest that to access some types of support, such as respite care, parents are made to feel like they are "failing" and must have already reached a place where they are finding it difficult to cope. Further, HCS works well for parents skilled at advocating or where there is a helpful HCS worker. Even though the supports are there, families may not know about them, or they must navigate the system to prove their eligibility for support. This leaves some families without the support they need.

Children's Services of the Alberta government has been recently restructured. While the policies and services have remained essentially the same, the services are now delivered by 18 regional authorities, called "Child and Family Services Authorities," each with their own board, as part of a community-based system which will allow services and programs to be planned according to local need. There are four pillars of the new structure:

- community based services
- early intervention
- integrated services,
- and improved services for aboriginal children.

All services are governed by the *Provincial Standards for Services for Children and Families*, which articulate what areas of services are available. The services include child welfare, daycare, family violence prevention services, services for children with disabilities, early intervention programs, and court services and mediation.

The authorities provide direct funding to families who have children with disabilities for therapy, respite, transportation to medical facilities (in or out of province), special diets, and so on. While other departments have experienced substantial funding cuts, services for children with disabilities have not. There is no official ceiling on the level of individual funding provided — families apply based on their needs, and can appeal any decision. While the appeal process may be intimidating for many families, the

majority of appeals are successful.

As seems to be the case across the country, getting information and advocacy support is nonetheless a key issue, the child having to depend largely on the advocacy skills of the parent for his or her needs to be met. Parents who have children with disabilities, who are disabled themselves, have particular challenges in trying to get the supports they need to parent effectively. Often these parents end up involved with the Child Welfare system,[10] which does not always respond sympathetically or effectively to their situation.

It is too early to tell what the new structure will mean overall to services for children with disabilities, and whether, for example, it will ameliorate or exacerbate regional inequities. While government policy supports the concept of children being cared for at home, the older they get, according to some respondents, the greater the support for institutionalized care.

Education

While the Alberta government's renamed Ministry of Learning policy supports integration of children in regular schools, in practice, it is left up to the municipal school board to decide whether to include a particular child, based on the school principal's assessment as to whether or not that child can be adequately served. In reality, children who have disabilities cannot expect to be served in their local school. Children may be directed to special site schools specializing in their disability. The situation has been made worse by dramatic cuts to education spending which leaves schools to struggle to meet the needs of children without disabilities, and leaving little in the way of resources to meet disability-related needs. Indeed, one service provider in Edmonton described children with disabilities who may have been successfully integrated in preschool as "walking off a cliff" when they reach grade one.

Summary

This chapter has examined the policy frameworks of supports and services for parents of children with disabilities on social assistance. It has reviewed national policy trends, including implications of the Canada Health and Social Transfer, regionalization, the Child Tax Benefit, and the National Children's Agenda. Since childcare is an issue of particular importance, legal entitlements to childcare services was also explored. In each province, policy sectors seen to impact the labour force participation opportunities and decisions of parents on social assistance who have children with disabilities were reviewed. These sectors included social assistance, childcare, housing, education, and disability-related services.

The policy review found a number of trends. While the federal government has reduced transfer payments and withdrawn from responsibility in a number of policy areas, provinces have responded with budget cuts, restructuring and increasing regionalization of governmental responsibility. While all of the impacts of these changes are not yet entirely clear, one of the effects seems to be a reduction in many of the supports needed by families on social assistance who have children with disabilities. This includes reduced benefits and/or entitlement to childcare, education, health, welfare, and social housing. Welfare, in particular, has become increasingly stringent in all three provinces, with reductions in benefits, stricter enforcement and, in Ontario and Alberta, new work for welfare requirements, for which many parents, including the majority of those who have children with disabilities, are not exempt.

Positive changes have also been occurring, though some of these are yet to be realized, or could yet be improved. At the federal level, the National Children's Agenda, with its intent to address the needs of Canada's children seems like a positive move,

although it is still in the planning stage. The Child Tax Benefit could potentially benefit families on social assistance, if the claw backs were removed. Commitments to inclusion in childcare, education and community support provisions are evident in at least some departments in all three provinces. In some cases, the delivery of supports in these sectors appears to be positively effecting inclusiveness and access to supports for children and families. However, there are inconsistencies between, and within provinces.

In general, the current era is characterized by a tightening of budgets and reductions in support for Canadian families in need, including parents of children with disabilities on social assistance. It seems contradictory that these cuts come at a time when policies increasingly promote community living, community-based services and the rights of children. Still, it is preliminary to comment conclusively on the new policy frameworks supporting this group of families, since many governments and government departments are in the middle of their restructuring process.

Endnotes

[1] Given the substantial number of children with disabilities on welfare it could probably be argued that it discriminates on the basis of disability as well. Despite their excellent report, it should be noted however, that as with similar reports children with disabilities are not mentioned.

[2] Needless to say this has specific implications for single parents who have children with disabilities where the financial costs of caring for a child can be extensive, and where finding a partner willing and able to take on the responsibility of a disabled child can be daunting at best.

[3] See appendices for further discussion of legal parameters of childcare.

[4] Nonetheless as pointed out above only 18% of children needing childcare are served in regulated childcare facilities.

[5] The new education funding formula puts all school based childcare centres at risk.

[6] See appendices for further discussion of legal parameters of childcare.

[7] It is worth noting that not all agency people interviewed for this paper were aware themselves of this exemption, despite the fact they were advocating on behalf of these families as part of their mandate.

[8] Handicapped Children's Services provides funding for some disability-related costs if parents can demonstrate need.

[9] See appendices for further discussion of legal parameters of childcare.

[10] Several respondents commented on the increase of children coming into care because their parents are no longer able to care for them. These include children with disabilities.

VI.
PROFILE AND EXPERIENCE OF PARENTS ON SOCIAL ASSISTANCE WHO HAVE CHILDREN WITH DISABILITIES

Research Sample

The research involved interviews with 24 parents on social assistance who have children with disabilities. Twelve parents in Alberta/British Columbia participated and 12 in Ontario. These parents were, for the most part, contacted through agencies that provide support to such families.

It should be noted at the outset that identifying individuals on social assistance who have children with disabilities willing to be extensively interviewed was somewhat problematic, and certainly time consuming. Project restraints in terms of time and resources limited both the number of participants as well as the level of diversity. The sample was comprised of 19 white parents, four parents of colour, and one First Nations[1] parent. As well, because names of people were obtained through advocacy type agencies, the sample consisted of people who, for the most part, were "hooked into" services as opposed to social assistance recipients who might be more isolated, disconnected, and vulnerable. For example, the sample did not include any families who were homeless, though other evidence suggests that families on social assistance who have children with disabilities are particularly vulnerable to losing their housing. Having a disabled child (e.g., one with behavior difficulties that results in noise or damage to accommodations) may even directly contribute to eviction.

Research Results

Overview

As noted in the literature review, the situation of parents on social assistance who have children with disabilities is one that has, to date, received little attention. This preliminary research reveals a group of people who face substantial barriers in daily living, whose lives have been changed by circumstances largely beyond their control, and who struggle in a political environment that is increasingly unsympathetic to *all* single parents on social assistance, regardless of their individual situations. These are families whose voices are seldom heard, and whose circumstances and struggles are systemically made invisible. They also proved to be an innovative and passionate group of parents juggling the complex responsibilities involved in caring for their children, advocating for their children, and surviving in difficult circumstances and financial hardship.

Demographics

The children

The age range of children with disabilities in this study was from 19 months to 35 years of age,[2] with nearly all of the children under the age of 14. The type of disability ranged from children with Attention Deficit Disorder (ADD), through various syndromes

including Fetal Alcohol Syndrome (FAS), Tourette's Syndrome, Down's Syndrome, autism, to physical and/or developmental disabilities. The severity of children's disabilities varied somewhat, but all the children had significant need for supports and interventions far beyond what most other children require.

The parents

Parents ranged in age from 22 to 53. The average age of the parents interviewed was 38. Only four parents were in their twenties, the rest were at least 30. Fourteen of the parents were divorced or separated, seven were single, and three were living with their spouse/partner at the time of the interview. While most of the parents interviewed were mothers, the sample included two fathers.

Housing

Only one interviewee was living in a home she owned. Most were renting (18) or living in a co-op (5). Rent ranged from a high of $1,100 to a (subsidized) low of $215 per month. The average amount of rent was $580 per month.

The quality of housing varied from very poor to adequate. Some families lived in cramped or rundown apartments, basements with little light, and had insufficient furniture. Others lived in apartments, subsidized townhouses or co-ops with adequate space, and better conditions, generally. Those living in subsidized or co-op arrangements were better off physically and financially.

Two families had lived in their current housing for over eight years, while others (three) had lived there less than six months. The average length of residence was four years. On average, families had moved 1.8 times in the last four years with a considerable number (nine) who had not moved at all, and a few (four) who had moved at least four times. One of these families had moved nine times in the last four years, while another had moved eight times.

When asked if they had ever faced difficulties obtaining housing as a result of having a child with a disability, 12 families said they had not, though a few anticipated they might in the future. Eight interviewees said they had faced such difficulties. The remaining parents were unsure. Two parents said they constantly lived in fear of eviction due to their children's tantrums and noise, while another said her child destroys property and frightens other children. One parent cited stairs and pesticides as problematic to finding suitable housing, while another mentioned the child's tendency to run into traffic — housing that is away from high traffic levels tends to be more expensive.

Income

Incomes varied according to the number of children in the family, from a low of $650 a month for a parent and disabled child to a high of $1,866 per month. The average income was $1,280 a month. Those families who were receiving some level of subsidy for their disabled child (not all were eligible) were slightly better off, while those parents who were disabled themselves and receiving disability benefits were the best off financially.

All of the families were living well below the poverty level. In addition to daily living expenses, they incurred disability-related expenses such as laundry, special clothes, special diets, medicines, and equipment. Additional monies allowed for the disabled child were inadequate in most cases to meet the additional costs, causing further hardship to the family as a whole, including siblings.

Cuts to welfare provision — particularly in Ontario where, in 1995, they were cut by 21.6% — were devastating to families. None of the families were able to benefit from the

federal Child Tax Credit due to provincial government clawbacks from social assistance payments.

As well as cuts to welfare, families are also struggling with cuts to supportive services (e.g., respite care).

A Day in the Life of ____[3]

It's full-time stress with Molly [a five-year-old with autism]. She's destructive. Everything in the house is locked. She is always trashing the place. It's in constant need of repairs. There are locks on all the doors and bars on her bedroom window or she would jump right through the glass. When Kelly takes her out, they need another adult present to help restrain her. She has no fear, jumps from high places, runs into traffic. She has to be watched very carefully to be safe.

Ann is 19 months old. She has seizure disorder and developmental delay. Since the seizure medication she's much better. We're not involved in playgroups — we just stay home. She doesn't sit up, or hold her bottle — she has to be fed every three hours. By the time my day is done, I'm tired.

My day starts at 5:30 a.m. Robert gets up and starts "barking." I then clean him, wash his hair, do his teeth, and get him dressed. Each step is a major struggle. I have to use tricks. After breakfast, I take him by the hand to the [school bus]. When he is at home he is glued to my side. (This is a child with several disabilities including ADD and Tourette's Syndrome. A medical assessment indicated, "Many of his premeditated and episodic, aggressive behaviors still persist, making Robert's management an ongoing nightmare.")

Stuart is very active. He won't go to sleep and sleeps on average four hours a night. His appetite varies greatly. He is unbalanced, but tries everything. He likes play dough, kids, books, swimming, and so on. There's nothing he doesn't want to do. He has no fear. His [brain] tumor causes mood swings, sudden anger, and loss of mobility. It affects him differently on different days. When it increases, the pressure causes a lot of pain. He may have several very bad days followed by several good ones.

For the parents in this study, the day usually starts fairly early, and the physical effort involved with caring for their child with special needs is considerable. Many parents talked about the enormity of just getting their child or children up and ready for school or daycare. Each task, as the parent above notes, is a major struggle. As many of the children had abnormal sleep patterns, some parents have already been up for a good portion of the night when morning arrives, and therefore are exhausted before the day has begun.

One of the key elements in the "average" day however, is that few days are predictable, and parents must deal with unexpected behaviors, changes in the disability, or information from a professional that is new and upsetting. If the child has rages associated with his/her disability, then the caregivers may not know what might set the child off; nor do they know how violent a particular episode might become. Many parents seemed to be waiting for the next crisis to arrive. Periods of relative calm were regarded by some with suspicion. For many parents, however, periods of "relative calm" were uncommon.

Needs and Support

The parents were asked about what supports they had in place for their children, whether or not they were satisfied with the current level and kind of support, what demands such supports made on them in terms of time for co-ordinating, advocating, transporting, and taking their children to appointments, and how they would manage were they to rejoin the paid workforce.

Childcare

> *Usually I get someone once and they find it too hard. If [my daughter] is agitated or frustrated, she destroys things, rips up paper, turns on all the TVs and lamps and fans. Babysitters come once, then it's the hunt for a new babysitter. When they see forms for Family and Social Services, they say " I don't think I want to do this." I can't take her anywhere, so we have a steady stream of strangers in the house, which is a trust issue.*
>
> *There's no money for childcare. I couldn't get a paid job and get the childcare I need. It prevents me from going out and looking for any old job. I have to think of after-school care, people to transport them to and from school. [And then the problem is] finding people skilled enough to take care of her, who will be able to keep her safe.*
>
> *He's never had a babysitter. I couldn't get childcare before because the centre wouldn't accept him because he's bigger than the other kids. I don't think I could get the childcare I'd need to work. It would be a major issue. I would be totally exhausted. Even not working, I am.*
>
> *The biggest issue is finding [a daycare] that will accept him and accommodate his needs. Daycare centres don't listen to you. I've talked till I'm blue in the face about how to handle specific situations, and they don't [follow my advice]. [If they would listen to me] Greg is not a difficult child.*

A significant proportion of families (15) had some form of childcare and/or respite care in place. However most arrangements were informal and irregular. Only two families had children in licenced daycare. Most had workers providing some sort of care in the home and this varied greatly from five hours a day, five days a week, to once or twice a month. As indicated in the quote above, a key issue for many of these families was finding someone to come into the home who is skilled enough to care for their children, and who is around long enough to be able to develop a relationship with the child.

Some of the parents had very little (e.g., once or twice a month) or no respite care at all. One young mother was afraid of leaving her child with anyone. Because the child's disability was the result of the child's father abusing her when she was a baby, the mother had difficulty trusting anyone. Yet, she was clearly in great need of a break. Other parents were simply unable to find anyone who could manage their children's behavior or respond appropriately to his or her needs.

As the children get older, they may not be independent enough to be left alone, but resist having someone there to care for them. It is also sometimes more difficult to find caregivers as the child gets older, particularly if there are behavioral problems. And yet childcare subsidies, regulated childcare, and respite care are likely to be reduced or disappear altogether as the child ages.

While a couple of parents seemed confident that they would be able to obtain appropriate childcare if they went back to work, most were not. Indeed a considerable number (seven) had tried to work and/or return to school and had been prevented from continuing due, among other things, to the lack of childcare. Said one parent who tried to go back to school, "the issue of childcare was 'a horror show.'" Another mother had found excellent childcare while she worked, but it was so far away that she could not get there from work in time at the end of the day. One mother had actually started her own unregulated childcare service as a way of addressing the need to work and access childcare for her daughter, only to find that money allotted to including her child in childcare could not be directed to a service she herself was supplying.

The sample was not large enough to indicate any differences in access to childcare with respect to whether or not a family lived in a

rural versus an urban area, or due to barriers such as racial discrimination or a lack of culturally appropriate options.

School

Emma is in grade three at a neighbourhood school. She's in a regular classroom, with an Independent Personal Plan (IPP) program — a program developed just for her. There are no adequate supports. She needs someone to be there all day to help her learn. I'm trying to get her an aide. I've been advocating for her supports for two years — it takes most of my time. The school has read the reports from the Hospital [yet] they don't believe she's disabled.

Molly's in her neighborhood school after a year-long battle at the school board. My daughter had been thrashed around and beaten at the [first] school she was at. They were into "restrictive measures." They had given her a split lip and bruises. When I said [to the principal] this was child abuse he said go ahead and call child welfare. At her second school they treated her the same way. She was in a class of eight kids and six aides and they couldn't manage them. Before I [caught the teachers in the act of abusing the children], Molly would come home with scratches under her armpits, bruises, and a puffy face from sobbing. She hadn't eaten her lunch, and often had wet clothes. They would say things like, " Get her under control or she can't come to school." She stopped wanting to go to school. She's now in a neighborhood school, same as her sister, in a class of 26 with an aide, and she does just wonderful. The principal is excellent. It took blood and guts to get her in the school she's in now — a whole year of tears and fighting for the rights of my daughter.

No, the supports are not adequate. She should have had a teacher assistant years ago. She's so far behind it's scary. I'm not confident supports will continue. At any moment they can change their mind and pull the rug out from under your kid. I am extremely active in my child's schooling, always there... to keep an eye on what's happening with Hannah .... I've learned to keep a close eye on the school. I spend at least two hours a day working with her on what she hasn't done in the day. I spend four or five hours a day — taking her, dropping her off, I go to the classroom at least once a day to talk to teachers, resource room, find out what's happening, constantly advocating.

I am very satisfied [with his school]. His teacher is excellent. He could not be in a better class.

School has been the most helpful thing in my life. (Nonetheless, this parent was called to the school at least once a week, and asked to take his son home when his behavior was "out of control.")

As might be expected the experience with schools varied greatly from those parents who were "extremely satisfied," to those who felt the level of support was inadequate, and those who had faced all-out battles with school authorities. There was a great deal of inconsistency in how children with disabilities were dealt with, even from school to school in the same board of education, or within the same school with a different teacher or principal. One parent felt that living in a poor area further reduced access to supports, and that had she been living in a better area of town, school supports would have been more forthcoming. Another spent considerable time and energy transporting all four of her children to a school in a different part of the city in order to access supports. It was also clear that parents lived in continual fear that whatever supports were in place — adequate or not —might disappear at any moment. Some parents were particularly concerned about what would happen to the level of support as their child got older.

One mother was concerned that while she had managed, through advocacy, to secure education supports for her son in the neighborhood school, she had to allow her child to be labelled as more severely disabled than he really is. She comments, "He has special needs, but not severe like the school says. I'm going along with it for the extra dollars." She spoke of having to balance the current and future harms to her child created by labelling, and the benefits of needed supports. This view was repeated by a number of other parents.

Whether or not the parent was happy with the school situation, nearly all the parents were very involved with their child's schooling and spent many hours in the classroom, or talking to school personnel. Many also had worked very hard to find a suitable classroom placement for their child in the first place. Parents expressed the feeling that they had to be constantly vigilant in order to ensure their child's needs were being met. When asked how they would manage this level of involvement if they were working, most parents replied that they simply would not be able to do it. One parent, who spent five hours every day at her child's school, commented that this is the main reason why she feels she should not work.

Parents with children with behaviors that were violent or aggressive had the most difficulty finding a suitable placement for their child. One 12-year-old child with ADD and Tourette's syndrome had been out of school for almost a year, despite being assessed as having considerable academic potential. Even a treatment program supposedly intended for children with such disabilities was unable (or unwilling) to meet his needs. After considerable advocacy by the mother and others, the school board finally agreed to hire a teaching assistant, and allow him to attend regular school, part time at first, and, ultimately, full time.

Children with toileting problems were also not well served by the school system. One parent reported that the school would call her if her daughter "wet her pants." When she was working and she could not get there, her child would be wet all day. No one at the school would change her. Her daughter would also run away on occasion, and the school would not call her right away, causing her perpetual anxiety regarding her daughter's safety at school.

While most parents take for granted their child's right to attend their local school, children with disabilities are often denied this right. For these parents, access to an education for their child is a daily struggle. Parents on social assistance are further disadvantaged because they do not have the monetary resources to fight the system, hire tutors, or consider alternatives (i.e., private schools). On the other hand, they have time that parents in the paid labour force do not have, to be extensively involved in their child's education, a sole and important advantage that they would lose should they return to work. Returning to low-paying work would neither provide additional money for tutors, nor provide the time to be involved with their child's schooling, thus putting their children at an even greater disadvantage.

Several of the parents had encountered abuse of their child at the school, and when they tried to do something about it, the school in turn accused them of abuse. In one case, the mother had suspected abuse because the child came home with bruises and scratches under her arms. Finally, she witnessed the abuse directly and complained to school authorities. The school responded by reporting her to child welfare, "telling lies" about her as an abusive parent. A child welfare worker came to her home in the evening prepared to take the child into care. Only the intervention of a supportive group of parents prevented this from happening. The school eventually apologized, but the abuse at the school was apparently never investigated, nor was the abuse in other cases.

Access to disability-related supports was not the only education issue raised by parents, however. One First Nations parent indicated that access to culturally appropriate education was as important to her as disability related supports. She pointed to the challenges her son faced not only as a disabled child, but also as a member of a cultural community that had been systemically demoralized. In talking about her own experience growing up as a disabled First Nations woman, she described a history of low self-esteem, unwanted pregnancy, alcohol and drug dependency. She says, "I couldn't accept myself being aboriginal ... I was taught native people were just drunks." She later adds, "I was underestimated and called mentally retarded." With regard to her son's education, she comments, "I'd like to see First Nations workers go in the classrooms. They have them in the school, but not the class. It's like a mini residential thing all over again."

Therapies

I haven't been satisfied so far. We get the [appointments] all set up, she goes through these assessments, they say they'll call you to set something up, and then I never hear from them again.

Billy gets it at school – speech, occupational, physical, psychologist. I'm satisfied with the therapies, but he's not going to get them after June. I feel this is the calm before the storm. I'm not looking forward to the next school year.

She gets speech, behaviour and toilet training therapy. She has about four appointments a month, which take up about two to three hours each. I would probably miss too much work if I had a job and had to get her there.

He's not getting any therapies. I feel he needs occupational therapy and a behavior therapist. I keep hounding [the school].

I am very happy [with his therapies]. I can see the progress and improvements.

I think he would benefit from alternative therapies, but I have no money for this.

Again, as might be expected, the kind and availability of therapeutic services varies greatly between the three provinces where the interviewees lived, and within the same province or even the same city. A common complaint was that the child would be subjected to endless assessments but these often did not lead to any treatment. Some children were receiving extensive hands-on therapy — speech, occupational, psychological — through their school, while others were receiving only sporadic consultation services, or nothing at all. Those children who were not in school or linked to a preschool program seemed to be out of the loop for any kind of therapy. Therapies not covered by provincial health care, including non-traditional therapies, were not available to these children unless a relative was paying for them, or the funding for services was flexible enough to allow the parent to put other money (e.g., for respite) towards therapeutic programs for their child (e.g., therapeutic riding).

It is not within the scope of this study to measure and compare availability of services vis-à-vis the individual child's need. However, any therapy provided often seemed dependent on the parent's advocating for such services until they were in place. Their persistence, given the bureaucratic obstacles as well as the high levels of parental fatigue, was remarkable. Some parents had not been successful in getting the services in place, despite their efforts. In other cases, it was not entirely clear why no services were in place. It appeared in a few cases that the parents either did not know what services were available and how to access them, were too tired to pursue them, or had simply given up.

Medical

I'm very happy with my pediatrician. He has gone out of his way to look after this child. I can call him at 4 o'clock in the morning and he will call back in two minutes.

I am satisfied with the medical care she has received. They take care of her as well as me.

The doctors are very informative and available. They take the time to answer questions.

When she was first diagnosed, we were in and out of specialists like there was no tomorrow. Once again, because the school wanted report, after report, after report. It took up to a day any time we saw a specialist. If I worked nine to five, it would mean taking days off.

It was a whole day off for just a test — he'd be so tired and traumatized, I would need home support.

As with therapies, there was a wide range in the degree of satisfaction expressed in relation to medical services. Nearly all the interviewees in Ontario reported relatively positive experiences with the medical system. The interviewees in British Columbia and Alberta had many more complaints. The sample was too small to draw any conclusions from this geographical difference. It may well have been a function of the disability, diagnosis, and the individual doctors involved, rather than a statement about the system as a whole.

Across the board, however, parents and their children found assessments stressful and time consuming. The assessments seemed to come in clumps, where there were periods of time where assessments were more numerous, particularly during the diagnostic phase. It was not unusual for a medical appointment to take a full day, and for there to be three or four in a month. The emergence of a new disability or a worsening of ones already identified could have implications for medical treatment. For example, one child had only one kidney, which meant her mother had to be on constant alert for infections. If she got an infection, it required extensive medical intervention.

Nearly all the parents said that following through with medical appointments would be difficult or impossible were they to work. Indeed, one mother said she had postponed a necessary operation for her son, because she was too busy looking for work.

Recreation

She'd like to be a cadet, but they won't let her in because of her disability. At home she likes to do puzzles, dancing, and listen to loud music. She goes to a summer camp for handicapped kids. That way, she won't be turned down.

She'll be starting Special Olympics. She can swim; she can go off the high diving board. We let her go off the high diving board, we let her put wood on the fire, we let her fish, and she's right down there in the white water. We tried to get her to give up water skiing. They said I was overprotective because I was upset by her bruises.

I really want her to swim for safety reasons. I tried to get her in swimming lessons. I couldn't find any that would take her. I phoned everywhere to find someone to teach her to swim. I took her swimming myself and put her in a lifejacket. I had to bring two other adults. Even if I take her for a walk I have to bring two other adults. She'll run, hit, punch, run into cars. She doesn't feel pain.

As with so many other things, access to recreational activities and facilities was not something that most parents could take for granted. Many programs make no effort to include a child with a disability. Even a program intended for children with physical disabilities may exclude children with intellectual disabilities. A child's need for one-on-one supervision, his or her inability to

get along with other children, aggressive or violent behavior, fears that s/he may harm others, swearing in public, are some reasons parents say recreation programs reject their children. Said one parent, "Anything with other children is out of the question, even the theatre." For parents on social assistance, these difficulties are often compounded by a lack of money to pay for lessons, equipment, additional support and transportation. Accompanying the child to recreation may also pose a problem because of having to care for siblings, or not being able to afford the adult fee. Some children were able to have recreational activities only because the parent had received financial assistance from outside the family. Most children were able to attend camp only if they received assistance to pay for a support worker, and the camp fees were very low or subsidized.

Some parents reported positive experiences with recreation programs that willingly included their children. In one case mentioned earlier, a child who had been out of school for nearly a year because of his behavior was able to attend a parks and recreation program run by the city. The staff, though untrained, worked very hard to include him and the experience was very positive.

Transportation

> *I am very dependent on my car. Most of my time is spent driving.*
>
> *Wheeltrans is a hassle 50% of the time. I can't do anything spontaneous. If I take the [subway] I have to carry her up three flights of stairs.*
>
> *I live in fear of losing my car — it is the most important thing to me.*
>
> *It's embarrassing if he's acting up and we're waiting for a bus. People ask why I can't handle him. This happens often.*
>
> *[Transit for the disabled is an] appalling service, unreliable, overbooked, understaffed, underfunded. You have to go all over the city before you reach your destination. Once [my son] was stranded in a suburb in his wheelchair at night. They pick you up three to four hours early, and then you have to leave early. It drives us mad.*
>
> *This year we had an aide come to the house in the morning and take her to school. Before we had the aide it was hell, we'd all be late. If I had a paid job, I'd have issues getting my kids to and from school. We don't know if we can get an aide next year.*

Given the amount of time spent going to appointments and the fact that the children rarely attend a school close to home, it is not surprising that transportation is a major issue for nearly all the families interviewed. School buses used by a number of the children (nine) were difficult for children with behavioral problems, and there were frequent incidents of the bus company refusing service. Some children were unable to use the bus without an adult accompanying them. At least one child felt stigmatized by using the bus for disabled children and feared teasing from other children. In a few cases, the school provided a taxi.

Those families (five) lucky enough to have a car were somewhat better off. Though they really could not afford the cost of gas, insurance, and repairs, these parents felt that a car was a necessity. They reported living in fear of something happening to their car. Because of its central importance to caring for a disabled child, several parents remarked that the cost of a car should be subsidized. But even a car was not always a complete solution for several children, as parents had to enlist the help of another adult whenever they had to go somewhere.

Parents without a car used the public transit system or a taxi. The latter is a major prob-

lem for many children who react to the noise, crowding, and over-stimulation. It also greatly increased the amount of time required to get to appointments. As in the example above, parents dreaded exposure to the judgments of strangers who had no understanding of the situation. It was not unusual for parents using public transit to be asked to leave if their child was not behaving.

How their child would be transported to and from school, appointments, daycare, and recreational activities were they to return to work was a major concern for most parents.

Agencies

Because nearly all of the interviewees had been referred to the research project by the agency they were connected with, nearly all families in this study were receiving at least some services from agencies, including advocacy support. They described the support they were receiving from agencies as critical to their well-being. Services included respite care, advocacy, accompaniment to meetings with school, court proceedings, and the like, in-home nursing care, parenting classes, behavior management, homemaker services, medical supplies not covered by health care, help with filling out forms, and counselling.

Generally, parents using such services had advocated extensively to get them. They felt that even after fighting for a service for years it could easily and without warning disappear. One mother, herself disabled (she had a bone disease and was physically fragile), reported that her homemaking services had recently, and unexpectedly been cut off. Parents were concerned that this is increasingly likely to happen, since the agencies they depend on are facing cutbacks and insecure funding.

A considerable number of those interviewed had come in contact with child welfare authorities and generally these experiences had been profoundly negative. Those parents who had tried to report abuse of their children by other caregivers said they had little success. While children with disabilities are more vulnerable to abuse, these parents found child welfare ill-prepared and unwilling to try to help their children. One parent had tried to get assistance for her child who had been sexually abused. At first, the authorities did not believe she had been abused. When the abuse was confirmed, they refused to provide counselling because the child was developmentally disabled. In another case, a mother, having just left an abusive husband put her child in care for three months when she became physically ill. When she tried to get her child back the child welfare agency refused to release her.

Personal Support

> *My boyfriend is a godsend. So is my father. They give me transportation if I need it, help me pick up groceries, take Jolene to appointments, talk with me about things like what the next step is.*
>
> *I don't get much support — that's always been my role.*
>
> *My mom is sick and we're not very close to [my husband's] family. They think this is not autism but my parenting. They think autism is about brain damage. [There are] four sisters — if they would help it would be a leg up for us.*
>
> *I have no family around here for support. That's why she went into care. I was sick; there was nobody to help. Instead of sending out a homemaker they took her away and never gave her back. I do it all. She was taken away under the assumption I was to blame for the way she is.*
>
> *My mother is very supportive; my friends are very understanding and supportive.*

The support network is another place I can go and vent. My neighbours will take Tracy for a walk to give us a few hours of normalcy.

People have been amazing, especially at the beginning. Friends listen, drive me around. Someone gave me six months worth of diaper service. But sometimes I feel I have no support and am very alone.

While some parents clearly had support from family and friends, just as many did not. Some parents' extended families were many miles away and therefore could only be of minimal assistance. Others simply could not deal with the disabled child, even in some cases blaming the disability on the mother. Grandparents often could not help because they themselves were sick or had their own problems (e.g., alcoholism). It is important to note that even in the few situations where the parent was relatively well supported by friends and/or family, they feared that their friends would tire of their problems and/or burn out. Those who received help from their families were then often expected or felt obligated to reciprocate. In at least one case this reciprocation was substantial and included cleaning, shopping, laundry, cooking, taking the parent to the doctor, and shoveling snow. Even if families were available, however, most interview participants seemed reluctant to ask them for help, perhaps because they feared they would be expected and unable to reciprocate.

In situations (nearly all) where the other parent no longer lived with the family, he (or in one case she) was rarely mentioned as providing any kind of support. In several cases the father took an interest in the non-disabled siblings but paid little attention to the disabled child. In some cases (three) the father was thought to have caused the disability in the first place through abusive behavior (e.g., shaken baby). One mother had left another country to escape an abusive spouse, while another had become pregnant with her child as the result of a rape. A considerable number of women had suffered violence at the hands of former spouses and/or sexual assault. Another noted that the father was a schizophrenic and that she tried to keep him and the child separated. In cases where there was a custody battle, this has added substantially to the level of stress. In a couple of cases, the father had kidnapped the children. One woman's husband (who had deserted her when he realized their child was disabled) had threatened to sue her for having given birth to a disabled child, when she appealed to him for financial support.

Additional Supports

When asked what additional support they needed that they were not currently receiving, parents were quick to respond. For most, at the top of the list is additional financial support. One mother had just ordered a walker for her son that would cost $5,200 and would not be covered by the provincial health care plan. "I have no idea how I will pay for it" she said, "but it is the only way my son will ever walk." Another mother, concerned her other children were affected by the time and resources directed toward her disabled child, said she would like enough money to carry on an ordinary life for all her children. She worried that without enough money for extracurricular activities, they were at risk. "I feel punished, and my children have been punished for my decision to help [her disabled child]."

Other things that required greater financial support included better housing, a computer, surgery (for the parent), food, nutritional supplements for allergies, and a car.

Some parents said that more physical help at home would make things more bearable, while for others childcare/babysitting and respite care were at the top of the list.

The Lives of Parents

Role of the parent

> *I'm everything — I'm the playmate, storyteller, therapist, disciplinarian, advocate, cook, and parent.*
>
> *It's different for a man in an advocating role. When a woman gets upset she's a hysterical housewife, but if I get upset I'm an abusive male. Men lack the skills and upbringing to do this job.*
>
> *I volunteer at school for almost everything. It's a full-time job getting her what she needs. If I was working it would affect my capacity to get her what she needs. I am Hannah's advocate and an advocate at [agency for families].*
>
> *It takes a lot of time, with doctors, finding daycare, taking him for tests, finding allergy information, going to the library, nutritionists, finding out what the system provides.*
>
> *I spend almost every waking moment with her, from getting her ready for school — it's an all day project. The only time I have for myself is when she goes to sleep. It's a constant fight, except weekends when she's at respite. It's the only time I can relax. I do telephone calls, meetings, more telephone calls, follow up on last week's calls.*
>
> *No one paid any attention, though we knew right from day one [that their child was disabled] — until I started yelling and screaming and demanding that things be done. They hope you'll eventually give up.*

While some parents may be better at it than others, and while some parents may have greater success than others, without exception every parent interviewed spent an extraordinary amount of time advocating, co-ordinating, and accessing services and supports for their disabled child. Phone calls, meetings, filling out forms, appointments, research, carrying out therapeutic exercises, volunteering in the classroom, preparing special diets, doing extra laundry, and acting as playmate were just some of the tasks undertaken every day by these parents. It is little wonder that most of them were exhausted and could not imagine how they could possibly rejoin the labour force.

The time required for advocating had periods of intensity. One mother reported spending five hours a day for an extended period just looking for respite care. Another spent several hours every day trying to get a school situation sorted out. A search for one service can lead to multiple phone calls. As one parent said, "You make a hundred phone calls to make another hundred phone calls."

Some of the parents had found that advocating on behalf of their children was a risky business. Some parents reported being accused of abuse or neglect because they were advocating for their child's rights. They suggested that service providers sometimes use this as a tactic to intimidate and silence outspoken parents. They further felt, as parents on social assistance or as single mothers, that they were more likely to be judged, and less likely to be believed if it came down to their word against a professional's. A number of parents said they had to walk a precarious line between advocating enough to get their child the needed supports, but not so much that they would risk retaliation by professionals in the systems that provide them. For example, one mother found herself being investigated by child protection authorities after she complained of abusive treatment she had witnessed her daughter suffering at school (see above). In another case, the child was in fact taken away when the mother tried to advocate on her behalf. As another mother comments, "If you do advocate, you run the risk of reprisals for yourself, your child, or both." Despite the fact that some parents feared repercussions if they advocated too strongly for their children, they continued to do so.

Parents were asked if there was support or

care for their child that they felt only they could provide. While the answer was somewhat mixed, it was clear that most parents felt they were the best ones to offer much of the care, and there was no replacement for the love they felt for their children. While they clearly wanted supports and services, the majority felt that even with adequate supports, they would continue to play a time-consuming and demanding primary role. They made such comments as, "I'm the only one with the time to do the reading, look into things, like alternative medicine." "I'm the only one with the understanding and true knowledge of her disability." "I give her the best care." "Who would do as good a job as I'm doing? Who would last with him?"

Impact on the Caregiver

> *I should have had a nervous breakdown, but I didn't have the time.*
>
> *I just get the feeling that no one cares. We're out here all alone and no one is there if you fail. It's very discouraging.*
>
> *I'm exhausted. Parents with children with special needs are not receiving enough support to keep their kids out of institutions.*

There was little question from the interviews that most of the parents were experiencing very high levels of stress. Several parents cried throughout the interview, while others talked of times in the past when they had "broken down." Many volunteered that they were either on anti-depressants, or were under psychiatric care as a result of stress. Several were suffering chronic fatigue syndrome. The overall impression was that nearly all of the parents interviewed were living very close to the edge physically, emotionally, and psychologically. If they appeared to be managing now, they had usually suffered very difficult periods in the past.

As indicated in the literature review, other studies have demonstrated that parents of children with disabilities suffer very high levels of stress. In the case of parents on social assistance, stress is exacerbated by a lack of money, which contributes to constant anxiety, low self-esteem, depression, isolation, lack of support, and other factors such as conflict with ex-spouses, or conflict with service providers. Interaction with social services is often a source of ongoing stress and anxiety — a sense that at any moment their financial support could be reduced or cut off.

Constantly needing to advocate for services, funding, and support appeared to have taken a tremendous toll on parents. Some of this was mitigated by the support of an advocacy agency, or the understanding and support of a worker. On the other hand an insensitive or unkind worker could make things much more stressful. One mother reported that a certain worker would ask her how it was going. When she replied it was tough, he responded that if it got too tough, he could always find other parents for [her daughter]. Indeed a comment from several parents was that the individual worker (or teacher or other professional) they were involved with had made all the difference in whether or not they received the supports needed. It was the luck of the draw which person they ended up with.

Parents also described the positive impacts they experienced in their role as a parent of a disabled child. They described the deep love they felt for their child, and the ways they had grown and changed through their parenting and advocacy experiences. In most cases, the lack of services and resources, and constantly having to advocate for them appeared to be a greater source of stress than actually caring for the child with the disability. For some of parents, the experience of raising a child with a disability had allowed them to develop new skills and to see themselves differently. Said one mother, "I'm a handicapped advocate now. I used to be quiet and shy. It's mostly me

standing alone. I'm sorry for those who don't have my nerve." Others commented that they had joined organizations where they were now helping other parents.

The road to social assistance

> *"Allan" held a highly responsible job that required him to travel regularly across North America. He had all the trappings of a middle-class lifestyle – a house in the suburbs, a car, decent furniture, and so on. When his wife left him, leaving behind two young children, he thought he would do what mothers would do in the same situation – put the children in daycare and get on with his life. But it didn't turn out to be that simple. Behavior in his youngest child that he initially attributed to his wife's departure made placement in a daycare impossible. After struggling to maintain his job for several months, he finally proposed to his boss that he take a six-month leave to stabilize the situation. By the end of six months it had become clear that his child was disabled, and the disability included aggressive and, at times, violent behaviors that were not going to disappear any time soon. Allan never made it back to work, and, within a year, he was forced to declare bankruptcy, and obtain social assistance. He lost everything including his home and his car.*

The majority of those interviewed said that the responsibilities involved with having a disabled child was the primary reason they were on social assistance. While not everyone had ended up on social assistance, at least initially as a direct result of this, it was clear from the study that almost everyone[4] remained on social assistance because of their caregiving responsibilities. As one parent said, "I became 100% unemployable."

Some parents had been on social assistance before (eight) and gone back to the workforce, while the majority had started receiving social assistance within the last four years or less.

While having a child with a disability was a primary factor in why these parents were on social assistance, it is important to note that most of these families faced additional obstacles to employment:

- Some of the parents (five) had more than one child with disabilities. Two parents had three.
- A considerable number of families (nine) had more than three children.
- A few were very young and had little education, while others were older and had not worked in a long time, making it more difficult to gain access to the workforce.
- Many were suffering from depression.
- A considerable number[5] had experienced physical and/or sexual assault, and were likely suffering from post traumatic stress syndrome.
- Some of the children had themselves been abused, and because of their disability they were given neither psychological help nor protection.
- Some faced workplace barriers because they were themselves disabled or chronically ill (four), and/or experienced race or gender discrimination.
- Some experienced isolation and little support from extended family.

The impact of social assistance

> *Because I'm on benefits it's assumed I don't know anything about my child and her needs. I am dismissed as being unworthy of assistance, or as a poor mother. It's something I see at school all the time. Mothers on assistance — nobody listens to them. I wouldn't have half the problems I face at school if I was in a nuclear family. At 40 I hate being treated like I'm stupid because I'm poor.*

[Being on benefits has affected me] positively because now I have the time to do what I have to do for [my children]. Negatively, because I don't have the money to pay for things. Time or money, you don't have both.

[Being on benefits means] a lack of self-esteem, fighting for your dignity. If you feel marginalized, so does your child. It's something that's not considered, the psychological affects of social assistance on parents and their children. Attitudes that somehow parents deserve to be poor are entrenched.

Being on assistance means not being able to feed or clothe my child properly. It means not being able to afford a movie. No toys, no books. Living so far below the poverty level stinks.

It has changed me. I have nothing to look forward to.

I think people want to contribute but you can get so beaten down and marginalized. People who have money just don't understand it. You can only let people buy you coffee so much. Then people beat the system just to maintain a sense of self. Rules and regulations to stop people beating the system work against themselves. Even the most honest people have to become fraudulent just to survive.

Social services have more power than the police. The police need a warrant but social services can just send a letter and come.

While most of the interviewees readily admitted that without social assistance they would have not survived, they also pointed to the negative side. Not having enough money, never being able to catch up with bills, having to scrimp in every way possible including using food banks takes its toll physically and psychologically. Some of the children required special diets that were not adequately covered. As with many other low-income parents, these parents would themselves go without food to ensure their children got the food they needed. Children with disabilities also often require special equipment and other aids (e.g., orthotics) that are not covered by welfare or health care.

They were also concerned about the psychological impact of welfare and poverty on their children. One mother says, "The kids are learning what welfare is...Here kids talk about 'oh, welfare day, I'm getting some money.'" As is indicated in one of the quotes above, they worry that being on social assistance not only damages their own self-esteem, but that of their children. In addition, they were worried that living in poverty added to their children's risk of social problems such as substance abuse: "Some kids buy pot, my son tried it at eight. He asked me what was crack. The area we live in, they learn stuff so young."

There was considerable bitterness and anger about how governments have stigmatized people on welfare and how everyone, regardless of their circumstances, has been painted with the same brush. "We're not welfare bums," says one parent, " We're caregivers providing a necessary service. Why can't we be recognized as such?"

The stigma and stereotypes associated with welfare were sometimes reinforced by individual workers who were responsible for providing social assistance services. One woman described crying when her welfare worker said to her: "You people come from out of town and depend on [social assistance.]" As this particular woman was both a recent immigrant and a person of colour, the worker's attitude may have reflected a range of prejudices.

Parents frequently commented on how much it would cost the government to care for their children should they collapse, and therefore, they asked, why could they not be given a little more money so this did not happen? A few parents admitted that they had used the threat of giving up their children to get needed resources. Other parents

had been threatened that their children would be taken away from them when they complained about inadequate services.

When the Ontario government cut welfare by 21.6%, no exceptions were made for parents who have children with disabilities, and it hit this group of parents very hard. For the most part, they regarded the cuts as cruel and punitive. One parent had fought for a whole year to get the handicapped children's benefit. He finally got it, and within days welfare was cut leaving him only $25 a month further ahead. Another parent called her MPP in a total panic. "How can I support my child on $200 a month? (the amount left over after rent)." "Put him in an institution," was the reply.

One mother's attempt to work seemed to have backfired. Her work was casual and unpredictable, but they based their deduction from her check on her previous month's earnings. If she did not make as much the next month she would be thrust into a financial crisis. At the time of the interview — a few days before Christmas — she had received about $300 for the month. It seemed there was neither support nor incentive for this mother to make the transition from welfare to work.

Another common complaint was that the social assistance system did not take into account the real costs involved in meeting the needs of children with disabilities. One mother said that her son goes through a lot of clothes because of his disability. When she bought $400 worth of clothes, using money from her partner's income tax, it was deducted from her check. Other costs include extra laundry and, as mentioned above, special diets, medicines and equipment.

Another frequent comment was that nothing was allowed for the caregiver or siblings. "I have no life — there's absolutely nothing for me," was a frequent statement. "Give me a holiday," pleaded one mother, "I've never had a holiday. I need a break." Parents worried about the impact of poverty and stigmatization on their other children who were forced to give up their own interests and activities. While some parents felt empowered as advocates for their children, there was a general sense of loss of respect, vulnerability and powerlessness. As one parent stated, "The system is not geared for support. It's there to prevent you trying to rip them off. To prove you are stupid and worthless."

As indicated in the quote above, people greatly resented the invasiveness of the system and their loss of privacy and dignity. "I have to tell them everything, many things that I don't think are any of their business — or else I'll lose my benefits," said one mother. The possibility of losing their benefits was a constant fear for some of the people in the study. One mother was being pressured by her worker to move in with her boyfriend as a way of getting off welfare. (She refused.) Another was afraid she would be cut off because her boyfriend lived across the hall.

One parent in the study had recently ended her dependency on social assistance, not because she had found employment, but because she had reconciled with her husband.

The pressure to work

Parents were asked if they were feeling pressure to return to the paid workforce and, if so, from where. With the exception of three families — two were excused from workfare because of their children's disabilities, and one because of the parent's disabilities — all the families felt pressure to return to the paid workforce. Some of the pressure was self-imposed among some parents (eight), for example, one mother who had promised herself she would only be on welfare for one year, or with others who were tired of having so little money for their kids or who owed money. Some of the pressure came from extended family and

society in general. But most of the pressure was seen as coming from the government, particularly in Ontario where workfare had been introduced, or in Alberta where the welfare role has been reduced by 50% and people can be cut off benefits even if they do not have jobs. While legislation in all three provinces specifically excuses people from having to work or look for work in situations where someone is caring for a disabled family member, many of the interviewees were unaware of this, and apparently so were their workers (or else they had neglected to inform their clients of the exemption). When one parent tried to inform the social assistance office of her eligibility for deferment, citing the correct section of the legislation, she was told the section did not exist.

In Ontario there was much bitterness about workfare. Said one parent angrily, "The government says we're not 'attached' to the workforce. They create a negative stereotype of anyone on assistance [and this] is a source of tremendous grief to me." Another parent spoke bitterly of how humiliating[6] workfare was and how employers were now trying to get workfare people to fill jobs formerly filled by paid employees. She gave the example of a workfare ad for a Girl Friday, requiring 80 words-a-minute typing skills. "Now employers expect you to work for nothing [The premier] has deliberately trodden on people like myself for the sake of businesses."

One mother who complained about continual "harassment" over apparent overpayments when she tried to work, had this to say about work, " If they had been fair, I might want to work more, but my incentive has been completely destroyed by [the social assistance system]. Now they think they can force us to work, by cutting off our benefits. That's not going to work for me. I'll just kill myself."

Unfortunately for some respondents, even the questions asked in the interview for this study seemed to reinforce the pressure to return to work. They felt the questions implied an assumption that returning to work was a desirable option.

Education, Training, and Employment: Background and Current Situation

Levels of education varied from those who had Grade 10 to those who had university or post-graduate education. With two exceptions, everyone had at least a high school diploma as well as additional courses (e.g., computers) and/or certificates (e.g., Business diploma). One parent had an MA while another had been recommended for a doctorate.

All the interviewees had worked in the past. While a few (four) had not worked in over 10 years, most had worked within the past five years. They had worked at a variety of occupations including sales, retail, clerical, nursing, teaching, media/entertainment, computers, factory, and childcare. Some had been in management, while several had operated their own businesses.

Two parents were working part time at the time of the interviews. While a few parents had not attempted to go back to work because of their child's or their own disability, the majority (16) had. They all had faced major obstacles in trying to juggle their responsibilities caring for a disabled child with working in the paid labour force. Most found it very tiring and stressful. Appropriate and reliable childcare was a principal difficulty, with parents reporting that they did not trust their babysitter (even the child's father in one case) and that therefore they worried about the well-being, even safety of their children. Shift work accentuated the problems of stress, fatigue, and childcare.

One mother described a typical day: "I was working at the Collections Company. I dropped her at daycare in the morning,

walked three miles to work, picked her up at the end of the day, took her home, put dinner in her, then it was bedtime. She hated it, and I didn't like it either. I felt guilty the whole trip. She started acting out, the daycare started complaining because of her behavior and because I'd be a few minutes late."

When asked why they left the workforce, the reasons were predictable. Said one mother who was working 50 hours a week, "I woke up one morning and I just couldn't do it anymore. I had a breakdown." Remarked another, "I couldn't go to work when the school was sending him home by 10 every morning." Others cited stress, pregnancy, the inability to take their children to appointments, illness, and, above all, childcare as the reasons why they left the workforce. A few had taken a leave of absence due to stress that had become long term, a few were laid off, and others quit because they feared they would be fired.

When asked whether they had encountered problems with employers because they had a child with a disability, a considerable number said "yes." Having to take time off for appointments and other emergencies was the most common problem, even with employers who were relatively understanding. Most workplaces lacked the flexibility these parents needed. Some parents felt they had lost out on jobs because they mentioned that they had children with disabilities, while one parent felt she was discriminated against simply because she was a single parent. One parent thought she was fired from a company where she had worked for 10 years because of frequent calls from the school, and because her ex-husband was stalking her.[7] Even a parent attending school received little in the way of understanding when she had to leave to attend to her child on the days when "he simply was not manageable."

When the interviewees were asked whether they anticipated problems in the future should they try to return to work or school, nearly all said "yes."

Personal plans for the future

I don't have a future.

I'd like to get my college degree, but the way I'm going right now I'm afraid I'll end up in hospital.

I'm going to have the operation done on my [brain] tumor.

I'm getting married.

I'd like to become an anti-poverty activist.

When asked what their personal plans for the future were, the interviewees were fairly limited in their responses. Many seemed to have difficulty conceiving of a personal future. It seemed that the day-to-day grind of survival inhibited any personal plans.

Plans for school, training, going back to work

I'd like to go back to good money, but I don't see how I could do it.

I tried to go back already, but I had to quit because I couldn't get any homecare.

I'd like to become a gardener, but I realize this is just fantasy.

I realize now that all I could manage is a part-time job, something nine to five that requires no brainpower. It's impossible to work full time and care for children with disabilities.

I'd like to work one-on-one with autistic kids.

I'd like to take a tractor-trailer training course — it's good money.

Due to the care and time involved [in looking after a disabled child], you can't dedicate yourself to a job. Doctors' appointments can't be made to suit your schedule and a child doesn't get sick nor have

therapy to suit [an] employed single parent. I also have two older boys with learning disabilities whose needs must be met at school. This is a constant battle and can only be done during the daytime.

Only four of the interviewees had given up any plans for returning to the paid work force. For them, though going back to work was desirable, it was impossible given their current circumstances. "My child requires 24-hour care," said one, "I just couldn't do it."

The rest all had plans to pursue something: hairdressing school, upholstery classes, addiction/alcohol counselling, work with First Nations people, media, tractor trailer training, computers, college, and gardening.

When asked what steps they would take to make this happen, their responses varied from, "I'll find a job," through "I'll go back to college," to simply "I don't know." Key to proceeding for most was being able to find childcare. While one woman said confidently, "I have everything I need to make this happen," most were less sure as to how they would turn their plans into reality, and where they would go for assistance and support. One parent stated, "This is a dream at this point. I don't know if I could make it work." Others mentioned they would turn to a support group, social worker, career counselling, and the Autism Society.

When asked how they thought social assistance could help them proceed, their answers varied from, " I have no idea. I'll have to ask," " through "They may put me through the training," to "They've done nothing to help. You can't even knock on the door." One woman feared they would tell her she was too old to take the training, while another parent complained that they will only pay for courses they choose, courses that train you for low-paying jobs. One person thought they probably wouldn't help her because she was "educated enough."

Indeed, when probed, it became clear that however much the interviewees wanted to change their circumstances there were sizeable obstacles to them achieving their goals. For instance, one parent talked of going to hairdressing school. But his child finished school at 3:00 p.m., and the course went to 4:30 p.m.. He had no idea how he would make arrangements to make this work because finding someone to care for his son was quite impossible, and he was doubtful the school would accommodate his having to leave early every day.

Some parents were clear that the most they could manage would be part-time work. But as some of the parents seemed to have training backgrounds that qualified them only for lower paying jobs, and others were reluctant to take on higher paying but more responsible positions, it was probable that working part-time would not improve their financial situations.

Above all, given the responsibilities of these parents — the endless advocacy, phone-calls, appointments and so on — the general sense of exhaustion, to say nothing of the unavailability of affordable, appropriate childcare, it is difficult to imagine how returning to work or school would be possible for many of these parents. This was particularly so given that a considerable number had tried already, and had been forced to leave the workforce.

Employer Supports

The interviewees were asked what support they thought they would need from an education or training setting, or from an employer in order to pursue their goals. Nearly everyone said that understanding and acceptance of their situation was key: understanding if they could not make it to school, understanding if they received doctors' calls at work, understanding so that their hours allowed them to pick their child up at daycare at 6:00 p.m.. Along with understanding, was the need for flexibility, for example, if they had to take time off when their child was in hospital, or if they

had to make personal calls during worktime, or if they had to attend appointments.

Key Challenges

The respondents were asked what would be the key challenges they would face in getting back into education, training, or the workforce, given they had a child with a disability. The key challenges included:

- Hours that fit with the family situation
- Age discrimination
- Discrimination because they were single parents or had a disabled child
- Finding appropriate, stable, and affordable childcare
- Juggling appointments
- Juggling caring for the child — getting her up, dressed, fed, and so on
- Unpredictability of child
- Getting workers to accept parent's disability
- Fatigue

When asked what worried them most about going back to work, education or training, they responded:

- Being able to cope with everything
- The children's safety
- My child ("The job wouldn't worry me — my child would.")
- Finding someone trustworthy to care for my child
- Being able to hang onto employment — "If you lose your job, it takes months to restore welfare."
- Lack of support from social services
- Fear that they will receive calls from school, daycare, that their child is acting out
- "If I do get a job and he's up at night, how can I go to work?"

Something to Look Forward To

Lastly, the interviewees were asked what they looked forward to. While some struggled to identify anything, most, despite the apparent bleakness of their situations, were able to come up with something:

- Summers, going to the beach
- Contact with other adults
- Being me again
- Getting married again
- Seeing my son do things for himself — I don't take his development for granted
- Seeing the kids improve
- Tracey getting into school
- Going to college
- Independence
- Watching my kids grow
- Sleep
- Being a leader in something

Changing the System

> *There are over 5 million poor people in Canada, nobody knows we are here. It's time we got up and started shouting and it's beginning to happen....People are tired of living on their faces, they want to get up on their feet.*
>
> *There are a lot of things I don't like about the system. I'm grateful we're not in a third world country, but we're not far off from that.*
>
> *Government has to listen to people. Let me tell them what I need.*

Parents were asked what changes they would make to the current social assistance system to make it more supportive of their situation. Many felt drastic changes to the system were needed. Here are some of the parents' suggestions:

- *Families who have children with disabilities*

should be in a separate category and be in a different program that takes into account their needs (e.g., diet, glasses, dental work, laundry costs, and the like).

- *Programs should take into account the fact that some families are far from extended family and other sources of help.*
- *There should be more support for families who have children with disabilities.*
- *There should be more compassion.*
- *Families should be allowed to keep money from bursaries, income tax, child tax credit.*
- *There should be recourse beyond the supervisor.*
- *The benefit levels are okay for toddlers but are inadequate for older kids; they need more food.*
- *There should be more information and better access to real training programs.*
- *End the frequent and arbitrary withholding of checks.*
- *Get rid of [social assistance] and replace it with a guaranteed annual income with full medical benefits — including some form of pharmacare where you get all your medication and aids for daily living, wheelchair, crutches, and no b------ to get them.*
- *There should be more money for transportation.*
- *There should be more money for childcare.*
- *There should be more money for training.*
- *There should be more money for alternative therapies and nutritional supplements.*
- *There needs to be recognition of the stress of having a child with a disability, and provision of respite care without labeling the parent as a poor mother.*
- *Social workers should be able to advise you about things. They should help you get out of your situation. There should be better advocacy in place.*
- *Pay more attention to individual family needs to make life as normal as possible. They don't consider a phone a necessity, but it is if you have a disabled child.*
- *Make it so social workers can't lie to you. Have other people available besides the supervisor to whom you can go, and make the fact well known.*
- *Social assistance should be replaced with a pension.*
- *Give people money who truly need it. Because there are people who defraud the system, the government seems to think no one needs it.*
- *Make it legitimate that I'm a caregiver, not a welfare bum.*
- *If they are going to send you to workfare, give training that you will benefit from, work that you are interested in, that will lead to independence.*
- *They should help me get more skills and support me while I'm doing this.*
- *Parents should be honoured and encouraged. If society really cares about children like they say, then make it real. People need to realize social assistance is not about people being leeches on "my taxes." I am right now the basis of my child's life. If he doesn't get this help now, he'll have major problems when he's older.*

Endnotes

[1] The minimal representation of First Nations people was particularly regrettable given the disproportionate number of children with disabilities on reserves. This group would warrant further study.

[2] Only one parent of an adult was interviewed, the rest had children under eighteen years of age. This parent spoke of her current struggles, as well as her son's childhood, in retrospect.

[3] Names, and any identifying circumstances have been fictionalized for purposes of confidentiality.

[4] Except for those who were themselves disabled.

[5] The interviewees were not asked whether they had suffered abuse unless it came up. Given the number of parents who volunteered this information, it is likely that the number who had experienced abuse was higher.

[6] Given how victimized and humiliated these parents feel already by the system, one can only imagine what they are feeling as even more punitive measures (e.g., mandatory drug testing) are being contemplated by some governments.

[7] As noted in the literature review it is not unusual for single mothers who are trying to retain employment to be sabotaged by ex- husbands.

VII.
POLICY DIRECTIONS

There is an urgent need for policy change and program development to meet the needs of families on social assistance who have children with disabilities. These families are clearly falling through the cracks in the system.

Families interviewed in this study were clear in their call not only for services for their children that would support their participation in all aspects of community and family life, but also for an income security system that respects and recognizes the value of the roles played by parents, be that in the public domain of the paid workforce, or in the private domain of the family and community.

Income Support

It was clear from this study that financial supports for these families are far from adequate. It was not uncommon for mothers to go without food so that their children can eat. Many, already living in poverty, experienced reductions in social assistance payments as a result of provincial social assistance cuts. They felt penalized and humiliated due to the financial impacts of choosing to care for a disabled child at home. Where supports were in place, or exemptions to work requirements available, parents were often left uninformed by workers.

Directions

1. The true costs of raising a disabled child and their non-disabled siblings should be considered in assessments for determining social assistance.
2. Governments should make efforts to determine the proportion of families on social assistance that are caring for a disabled child.
3. Workers representing relevant government agencies should directly inform their social assistance clients about work exemption rules and available benefits. This should be a requirement of the job. If needed, workers should receive training to do so.
4. Families on social assistance should have effective recourse (e.g., to a supervisor or alternative worker, or appeals process) if they believe they have been treated unfairly.

Transition to Work

It is clear that the amount of support required to enable parents to return to the paid workforce is considerable, and in some cases simply not feasible. In the latter case, parents' work as caregivers needs to be recognized and supported by providing them with a long-term secure source of income so that they can continue to care for their children.

For those who want to return to work or pursue an education, it will take a concerted and collaborative effort to ensure they will be able to do so. To do so, they need adequate and appropriate childcare, understanding and supportive workplaces, transportation, professionals who allow work-friendly appointment schedules, and more supportive schools with better resources. For this to happen, there will have to be an effort to raise awareness about the

reality for these families. For many of these parents a plan to work part-time would be both feasible and more realistic. But, at the moment, parents who attempt to do this are penalized by having almost every dollar earned subtracted from their benefits, and insecure income when work is unpredictable. Governments who ensure that low-income working families keep medical and other benefits are on the right track in one important aspect in supporting welfare to work transitions.

Directions

5. The unpaid work of caregivers should be better supported and recognized as work through the income security system, and treated as a valid, socially respected role.
6. Parents who have children with disabilities wishing to return to the workforce should be given greater support in doing so, including access to training for 'good jobs,' and access to the supports necessary to pursue training, education, or work (e.g., childcare, homecare, transportation) with respect to their disabled, and other children.
7. Parents who have children with disabilities on social assistance wishing to work part-time should be supported in this goal. This means that they should not be penalized for earning additional monies, nor should their source of income be made more tenuous and insecure as a result of working part-time. Arrangements for income support should be flexible, and guarantee an expanded level of income each month.
8. Allowances should be made for parents on social assistance to better their current and future situation, and that of their children, in terms of saving, or accepting money (from family, and so on) without being penalized for doing so.

Housing

Parents need a secure home base to raise healthy and secure children, and to pursue employment objectives. As this study confirmed, families who have children with disabilities often face particular challenges in obtaining appropriate housing. The difference between those families in the study who had secure housing and those who did not was dramatic. Families who were moving often were at risk for entering a downward cycle, which might well affect their children in the long and short term.

Directions

9. Governments at all levels should act quickly to increase the availability of cooperative, subsidized and accessible housing for families who have children with disabilities and others.

Childcare

As emphasized throughout this paper, and confirmed by the parents in the study, the lack of accessible, affordable, high quality childcare is a major impediment to single parents with a disabled child. Even if parents are not going back to work, early childhood education is as essential for children with disabilities as it is for all children.

Families who have children with disabilities often still need childcare for their children after most programs end at age 12 or younger. While the difficulties obtaining childcare generally dissipates for most parents as their children get older, for parents who have children with disabilities, the difficulties may intensify. There are limited programs available for these children.

Directions

10. Access to affordable, high quality inclusive childcare for children with disabilities should be facilitated by governments

passing legislation guaranteeing such access, providing the necessary supports (e.g., ratio enhancement), increasing the number of spaces available, and providing subsidies.

11. Parents with older children (e.g., those with developmental disabilities) should have access to a range of childcare and after-school programs beyond the age of 12.

12. Additional subsidies should be made available to low-income parents whose children require care beyond the age of 12.

School

Clearly, if parents must spend the amount of time advocating and assisting their child in the school system that most of the parents in this study seemed to spend, their role in the education of their children is as a significant barrier to their returning to work. Cuts to education and supports experienced by parents and children in all three provinces impeded parents' entry to the paid labour market. Reductions to in-school supports (e.g., speech therapy) add to the appointments parents must attend during working hours. Ensuring that children in schools have access to therapies and support in the school reduces the number of after-school appointments parents must arrange, and allows children to have a more regular and predictable routine. It also allows parents to work.

Governments should consider the full implications of cuts to special education and supportive services. Savings in this regard may well be offset by parents who, as a consequence, are unable to work, and are forced to remain or go on social assistance. Furthermore, children with disabilities who do not receive the supports they need to be successful in school, are more likely to be dependent in their adult lives.

Directions

13. Governments who have already initiated or who are planning cuts to special education and in-school supports should reverse their decisions.

14. Schools should be enabled and be required to offer a range of placements for children with disabilities, prioritizing full inclusion[1] in a local school, but also offering specialized support where appropriate.

15. Schools should be proactive in reducing the amount of time that parents who have children with disabilities must spend advocating for basic supports so that their child can gain access to an education. (Principals can play a key role in this by acting as effective case managers.)

16. In-school supports should be more equitably available across school boards and provinces.

17. Children with disabilities should have equitable access to the supports they need in a culturally appropriate education setting (i.e., in a school with First Nations programs or French language programs).

18. A focus on inclusive and culturally appropriate education should be incorporated into education pedagogy and teacher training.

Services

Families are in need of a range of services and, as indicated above, all three provinces are involved in significant service restructuring. Unfortunately, some families are falling through the cracks of this restructuring. In addition, the capacity of agencies to serve families is being restricted and reduced through government cuts to their funding.

Although this study included only one First Nations parent, statistics suggest that there is

a disproportionate number of First Nations children with disabilities. Because of this, special attention should be paid to the availability and delivery of culturally appropriate services to these children.

Directions

19. Governments should ensure that a range of quality core services (e.g., respite care, therapies) are available as locally as possible to all families who have children with disabilities, and that families are not subjected to arbitrary ceilings on monies available that fail to take into account their real needs.
20. Particular attention should be paid to the needs of First Nations children with disabilities.

Advocacy and Information

It was clear from this study that families spend an extraordinary amount of time finding and advocating for basic services, which stands as a major barrier to working. What was also clear from this initial research is that often families who are already struggling, are subjected to further stress and grief at the hands of professionals and systems that should be there to help them. Too frequently these services add to their clients' sense of powerlessness and victimization. It is incumbent on the social assistance systems, as well as on schools, agencies, childcare, and other professionals to be proactive in helping to minimize the stress on these families. It was also clear that because the attitudes and efforts of individual workers, professionals, and teachers, have such an impact on parents and children, efforts need to be made to ensure that such individuals receive the training, and the supports needed to do their jobs effectively.

It should be noted that some of these parents were too overwhelmed to organize and find such services as respite care, even though these services are available. Therefore, there needs to be more outreach to these families to make sure they are getting the services to which they are entitled before they reach a state of collapse. Agencies involved with these families should not assume that they are managing all right, simply because they have not heard from them.

There needs to be a commitment to ensuring a central point of access for information on services and for planning/coordination assistance to reduce the number of 'hoops' that parents must jump through. The system should support parents' efforts to access services to meet their children's basic needs. Accessing such services should not depend to such a large extent on the parents' advocacy skills, and their ability to sustain a high level of determination over time in the face of institutionalized resistance and inertia.

It should also not be so difficult to get information about services and financial supports. Professionals on all fronts need to be far more proactive in offering helpful information to these families. Governments could offer comprehensive booklets that include information on childcare, education, financial supports, assistive devices, respite, and rehabilitative services.

Directions

21. All professionals and personnel working with these families should undergo training to sensitize them and make them more aware of the challenges the families face and how their actions can positively or negatively affect them.
22. Professionals and other personnel should receive the supports and compensation needed, as well as reasonably sized caseloads, to ensure that they can provide effective service.
23. All systems available to these families should be made as accessible and free as possible from bureaucratic impediments (e.g., endless forms to fill out).

24. Professionals and personnel working with these families should be directed and required to be as helpful and supportive as possible (e.g., volunteering information about financial supports available and other services). Workers who have demonstrated a negative and destructive attitude should be redirected to other roles or employment.

25. Provincial and municipal governments should develop comprehensive booklets outlining what services are available for families who have children with disabilities and how they can be accessed.

26. Funding should be directed toward agencies that can support families in accessing information and services, and assist them in their roles of accessing, coordinating, and researching services.

Support for Families in Crisis

Many of the families were on social assistance because of marital breakdown, spousal or other abuse, or a crisis such as illness. Timely support to families might help to prevent a separation or divorce in the first place, prevent a single parent ending up on welfare, or assist a family in getting through a period of crisis such as illness of the parent or child. It needs to be recognized that primary caregivers experiencing divorce are in great need of support during the first one to two years of separation, if they are to be expected to get back on their feet. For parents who have children with disabilities experiencing divorce, the need is even greater, the stress is likely to be even more enduring, the challenges in getting back on their feet even more daunting. These contingencies should be considered in designing support for these families.

Directions

27. Families, particularly those whose children have disabilities, should be offered particular program support during the early years of separation and divorce, or following situations of abuse.

28. Workers involved with divorcing families (lawyers, judges, mediators, court appointed assessors) should have training specific to the needs of families who have children with disabilities.

29. Support systems, including emergency funding, counselling, and emergency respite should be in place to assist families in coping with crisis situations.

Transportation

Transportation was identified as a key issue for parents who have children with disabilities both from the point of view of its importance in getting children to appointments, and its impact on a parent's ability to work. As indicated in the study, many parents felt that a car should be considered a necessity not an asset, and that costs for a vehicle should be subsidized.

Directions

30. A car should not be considered an asset for families who have children with disabilities in any of the means/income tests.

31. A transportation subsidy should be provided for children with disabilities whose parent(s) are on social assistance or have low incomes. This is currently available to families without cars. It should be increased and expanded to include families with cars.

32. Transportation supports should be funded to aid the inclusion of children in school, daycare, or community programs (i.e., support workers to take children to the program; to make school buses accessible, and so on).

Recreation

Access to recreation was a primary difficulty for families in this study, yet as noted in the literature review, free recreation (and childcare) will reduce future use of other services by families on social assistance. For children with disabilities, it is a primary opportunity for socialization and inclusion in their communities. As was also found in the study, not only are children with disabilities denied access to recreation in a number of instances, but so are their siblings.

Directions

33. Paid or subsidized recreation should be made more broadly accessible and inclusive for children with disabilities and their families (including parents and siblings.)
34. Funding should be made available to provide the supports and resources necessary to include children with disabilities in inclusive recreation programs.
35. Training should be available for people who work in recreation and leisure regarding inclusion generally, and sensitivity to the circumstances of families who have children with disabilities specifically.

Child Protection

As indicated in the study, some families on social assistance who have children with disabilities may have contact with child welfare agencies as a result of their child being abused, or because their child was perceived as being at risk (e.g., because the parent is disabled). Other studies have indicated that children with disabilities are particularly vulnerable to abuse. Granted, the number of children who had suffered abuse in the study were few, however, it is worth noting that, according to the parents, the children in the study with disabilities who had been abused were not protected by child welfare, nor was treatment available to them, ostensibly because of their disability. It is also worth noting that at least three of the children were disabled as the result of child abuse.

Drawing conclusions as to how broadly based are issues related to child welfare and children with disabilities is clearly beyond the scope of this study. It is also not within the study's purview to give detailed recommendations in this regard. Nonetheless, the study suggests that there are issues in this area worthy of further study.

Directions

36. Child welfare agencies should examine their response to children with disabilities and their families to ensure that the response of the agency is appropriate and effective.

Employers

Families in this study indicated that if they are to return to work they will need understanding and supportive work situations. Workplaces that are already family friendly may be willing to provide this support, but others are either unable or unwilling to make special allowances. It is unlikely that this situation will change unless employers are made more aware of these employees' needs and their legal obligations to accommodate them, and are offered some form of incentive to do so.

Directions

37. Agencies involved in work-family initiatives should raise awareness in workplaces about the needs of families who have children with special needs.

38. Human rights legislation and guidelines should stipulate that families who have children with disabilities cannot be discriminated against based on their family status, and that it is against the law to do so.

39. Just as workplaces can apply for funds to make their workplaces physically accessible to people with disabilities, there should also be a special fund to compensate (for undue hardship) and encourage companies to accommodate employees who have children with disabilities.

Endnotes

[1] In order for inclusion to work, there must be a number of measures in place including appropriate in-depth training for teachers and teaching assistants, classroom support (e.g., teaching assistant, speech, occupational therapy etc.), the removal of physical barriers, and leadership on the part of the principal.

CONCLUSION

The current system does not always serve the best interests of children with disabilities, particularly those on social assistance. With the steady stream of cutbacks, this situation may get worse. It would be short sighted to give only token supports to these families. Society pays a larger price in the long term when supports are not provided and where children and families are left vulnerable and dependent on residual, last-resort forms of care. The opportunities for parents and children to make contributions to society are reduced, and the likelihood is increased that the children will require greater levels of care and even institutionalization throughout their lives.

When this report was prepared, federal and provincial/territorial governments were making pronouncements and devising plans for new initiatives to foster the developmental potential of all children. It is to be hoped that, years from now, legislators, policy makers, officials and ordinary citizens will look back with pride upon their efforts to keep seriously disadvantaged children with disabilities and their families clearly in view, and for ensuring that improving the futures of these children and families was a core aim of the programs being set in place.

APPENDIX
SUMMARY OF CANADIAN LAW RELATED TO CHILDCARE

This appendix examines the current law pertaining to childcare for children with disabilities whose parents are seeking labour force participation in Alberta, British Columbia, and Ontario.

In addition to the statutes that have as their primary purpose (or one of their purposes) the promotion and regulation of childcare services, attention will also be paid to those broader statutes and constitutional provisions which can dictate the manner in which such specific statutes are implemented, both by the governments which create them and by the agencies which operate pursuant to them. This includes human rights legislation and such other statutes as those dealing with health care consent, employment standards, occupational health and safety, and the like. In the case of the three Canadian provinces, which are the focus of this study, the *Canadian Charter of Rights and Freedoms* is the highest authority that can be invoked in calling upon governments and those acting on behalf of governments to respect people's rights.

The review of legal aspects revealed that there are two types of legal principles and provisions relating to day care for children with disabilities whose parents are seeking labour force participation. The first is positive entitlements that are available to any parents, regardless of their socio-economic status and regardless of whether their children have disabilities. The second is protections against discrimination based either on the disability of the child, on the fact that the person seeking to enter the work force is a woman, on the parents' low and uncertain income, or on or any combination of those grounds.

These categories may co-exist in the same statute. The central example in the area dealt with by this study would be when governments commit themselves to promote the development of childcare in various settings, and they also declare that some or all of these settings are by law required to be open and accessible to children with disabilities. Often, however, the positive entitlement appears in one statute, and the protection against discrimination is found in the general human rights legislation applying in the same jurisdiction.

Legislation governing childcare can itself be divided into two categories (both of which are likely to appear in the same statute). One is enabling legislation, which establishes the authority of the government to engage in the financial support of childcare. The other is standard setting legislation, which extends that authority to prescribe mandatory criteria of quality, either by the provisions of the statute itself, by regulations made under the authority of the statute, or simply by policy statements issued by the ministry responsible for the implementation of the legislation.

In each province and territory in Canada there is human rights legislation that is designed to ensure non-discriminatory treatment of all citizens who belong to categories — women and minority groups, including persons with disabilities — who have historically been disadvantaged with

respect to their equal enjoyment of the benefits of society. Constitutional and statutory human rights instruments go further than simply to interpret the ways in which statutes are to be applied. Even in the absence of a relevant statutory provision, human rights laws may require governments to take certain actions to ensure non-discrimination in their treatment of persons with disabilities or other protected characteristics. This is especially true where a government undertakes to provide a service, such as childcare, without making provisions for accommodating the needs of persons with disabilities in taking advantage of that service.

Ontario

Childcare in Ontario is governed by the provisions of the *Day Nurseries Act*.[1] The *Act* authorizes segregated programs to serve children with disabilities, and governs regulated childcare for children with a 'developmental handicap' up to the age of 18 years. For other children the ceiling is 12 years. While the Province does not have a policy of integration in childcare facilities for children with disabilities, there are apparently few segregated programs .[2]

In the government document, *Improving Ontario's Childcare System*, the report of the Childcare Review in August, 1996, a new approach is treated as essential, and in fact partially achieved. The report outlines the profound changes to service provision for disabled children over the last 20 years, from segregated to integrated, mainstream programs delivered by a wider range of public and private operators. The report further describes the available full or partial childcare fee subsidies and ministry funding for specialized support services, such as resource teacher programs.

Childcare policy has not fully evolved to meet the shift from segregated to integrated programs, especially with regard to cost sharing arrangements for children with disabilities. Consequently, a variety of different practices have evolved across the province, resulting in inconsistent treatment of families with disabled children. For example, parental contributions toward childcare fees are assessed in different ways. Some families are needs tested, while others are not.

In addition, special needs resource funding is not as responsive as it could be. It is considered part of a larger Ministry of Community and Social Services investigation of individualized approaches to funding of supports for disabled children. This is intended to make those services and supports more responsive to individual family needs (1996).

In reality, the Regulations under the *Day Nurseries Act* envision a system that is essentially segregated and staffed by persons who are specialized in meeting the needs of children with disabilities:

> 59.(2) Every operator of a day nursery for handicapped children shall employ in each such day nursery operated by the operator at least one person who holds the qualifications set out in subsection (1).[3]

Subsection 59(1) lists persons who hold a diploma in early childhood education or the equivalent academic qualifications, or are "otherwise approved by a Director." The Regulation goes on to designate who qualifies as a resource teacher in a day nursery:

> 60. A resource teacher shall be a person who, . . .
>
> (b) has completed a post-secondary program of studies approved by a Director that is both theoretical and practical and that relates to the needs of handicapped children; and
>
> (c) if working with multi-handicapped children, has a current standard Red Cross or standard St. John's Ambulance certificate in first-aid,

> or is in the opinion of a Director capable of planning and directing individual and small group training for handicapped children.[4]

The fee subsidy formula is also different where children with disabilities are involved from that applicable to typical children. Depending on the level of specialized support required, the province pays from 87 to 100% of the fee subsidy, whereas, in the case of services for children without disabilities, the province only pays 80% of the subsidy. Whatever is not paid by the province comes from municipal or private sources.[5]

The *Ontario Human Rights Code*, like its counterparts in Alberta and British Columbia, guarantees equal treatment for persons with disabilities within a "reasonable" scope. Unlike the other two provinces, whose human rights legislation invites service providers to argue that there are reasonable or *bona fide* limits to what the law requires of them, Ontario's *Code* maintains an onus on them to make "reasonable accommodation" of the special needs of persons with disabilities:

> 17.(2) The Commission, the board of inquiry or a court shall not find a person incapable [of benefitting from a service] unless it is satisfied that the needs of the person cannot be accommodated without undue hardship on the person responsible for accommodating those needs, considering the cost, outside sources of funding, if any, and health and safety requirements, if any.[6]

The end result can admittedly be the same, but the focus is on what the service provider is required to do, rather than what it can get away with. The Code provides that regulations can be made specifying standards to be applied when assessing what constitutes "undue hardship," but no such regulation has ever been promulgated. The Ontario Human Rights Commission has published its own guidelines, which say that accommodation must be made up to the point at which they would threaten the viability or change the nature of the enterprise.

As in Alberta, the Ontario government has begun the process of devolving both financial and regulatory responsibility for childcare to regional authorities. This seems likely to result in greater inconsistency in the quality and stability of such services. Interestingly, it comes on the heels of the federal government's own "downloading" when it replaced the Canada Assistance Plan (CAP) with the Canada Health and Social Transfer (CHST).

British Columbia

British Columbia is in the midst of transition from the previous "Special Needs Day Care Program" to "Supported Childcare." British Columbia has had a history of utilizing both segregated and integrated childcare placements for children with disabilities. A 1993 report of the Special Needs Day Care Review Committee proposed a phasing out of the segregated agencies. In response, the provincial government negotiated an agreement with the federal government to co-sponsor an $8 million four-year "Strategic Initiative Project," the Supported Childcare Initiative.[7] The project was jointly funded by Human Resource Development Canada and the British Columbia Ministry for Children and Families.

A government brochure promising that "By March 1999, British Columbia will be an inclusive childcare province" describes Supported Childcare as follows:

> Supported Childcare is a way of making sure children who need extra support are able to participate in "typical" community child-care settings . . . Inclusive childcare is childcare that includes every child, regardless of ability. It is childcare where every child is welcome, where every child belongs. ...Inclusive childcare means that all

> families have the same childcare choices, that all parents are able to decide for themselves where to send their children ...To make sure a childcare setting is ready to include a child who needs extra support, the setting may have to make some adjustments. . . . Supported Childcare makes those adjustments possible (Ministry for Children and Families, undated).

In 1996, the British Columbia Legislature passed the *British Columbia Benefits (Childcare) Act*.[8] This legislation is the statutory foundation on which the Supported Childcare Initiative has been constructed. The purposes of the *Act* are set out in s. 2:

> 2 The purpose of this Act is to implement a childcare system that will
>
> (a) promote the health, safety and well-being of children receiving childcare,
>
> (b) promote quality childcare,
>
> (c) improve access to childcare, *including childcare for children with special needs*, and
>
> (d) provide financial help to families with limited incomes who need childcare.[9]

This statute is now the authority for childcare grants and fee subsidies. When it was introduced, the government also announced that an additional 4,000 families where a parent was seeking employment and/or job training would qualify for childcare fee subsidies (Childcare Resource and Research Unit, *Childcare in Canada: Provinces and Territories*, 1995. Ontario: University of Toronto, p. 52).

With the introduction of "Supported Childcare," the province has taken a major step forward in ensuring integration and equitable access for children with disabilities. Whereas, under the old program, parents had few options and were largely restricted to a "specialized" childcare setting, which was often not close to home or work. Under the new program, the parent chooses the childcare setting for their child. The parent is then involved in determining what additional support the child needs. The parent also helps to determine which professional services — for example, speech and physical therapy, nursing care — are required while the child is in childcare.

Until the Supported Childcare Initiative was introduced, there seems to have been a presumption in British Columbia in favour of segregated childcare facilities for children with disabilities. Provincial regulations stipulated that "special needs" facilities had to have a staff/child ratio of 1:4 — the same as that required for groups of zero to three-year-olds. Above the age of three, and where disability was not involved, each staff person could be responsible for at least twice as many children. Government funding and/or subsidies were based on the additional staffing and equipment costs associated with the disabilities of the children involved. While the Ministry of Children and Families was responsible for the overall supervision and promotion of the childcare system, the Ministry of Social Services administered the subsidy program and the special funding for children with disabilities until 1993, when that function was assumed by the Ministry of Women's Equality (Childcare Resource and Research Unit, *Childcare in Canada: Provinces and Territories*, 1995. Ontario: University of Toronto, pp.50–52).

The government's brochure on the Supported Childcare Initiative (Ministry for Children and Families, undated) admitted that the previous system had favoured segregated settings:

> Right now, the Special Needs Day Care Program funds services to about 3,600 children across B.C. Under this program, most parents have little choice about what childcare setting to use — their child usually may only go to a "specialized" childcare setting. This

> setting may not be close to either your home or your work.

According to the brochure, parents will henceforth have a choice of more than just which particular day care facility their children will attend:

> You will help decide what training, equipment and staffing the childcare setting will need to support your child. And you will help determine which professional services — including speech or physical therapy or nursing care — your child will receive while in childcare.

Parents still pay the same basic childcare space fee as parents with children who do not need extra support. Low-income parents may apply for a childcare subsidy to help cover the basic fee. The amount of the subsidy is based on family net income as well as the number of people in the family. There is a maximum allowed, and the parent must pay childcare fees exceeding the subsidy amount. Where a child with a disability is involved, there is an additional "space-fee subsidy" of up to $107 a month, regardless of family income. In addition, the government will fund extra resources needed by the childcare setting such as special equipment, staff training or extra staff (Ministry for Children and Families, undated).

However, while under the old system, childcare and related services for children with disabilities were funded entirely by the government regardless of family income, parents must now submit to a means test both for the regular fees *and* the additional costs of special supports for the child. Affordability is likely to be a key issue for parents of children with disabilities requiring childcare.

Furthermore, with the advent of Supported Childcare, the likelihood of there being a case of discrimination based on exclusion from appropriate childcare services would appear to be significantly reduced. Prior to these changes, it would have been open to parents to bring a complaint under the Province's human rights legislation. *British Columbia's Human Rights Code* guarantees non-discrimination in services by s. 8:

> 8 (1) A person must not, without a bona fide and reasonable justification,
>
> (a) deny to a person or class of persons any accommodation, service or facility customarily available to the public, or
>
> (b) discriminate against a person or class of persons regarding any accommodation, service or facility customarily available to the public because of the race, colour, ancestry, place of origin, religion, marital status, family status, physical or mental disability, sex or sexual orientation of that person or class of persons.[10]

Once again it must be noted that the *Code* allows for "bona fide and reasonable justification" for unequal treatment. Presumably a childcare agency could muster the same arguments to satisfy that exemption that was alluded to in the text above at Note 4 in the discussion of the Alberta human rights legislation.

British Columbia's apparent commitment to end segregation in the childcare system also goes a long way towards resolving a second-level discrimination issue. It is one thing for a child to be denied access to any day care service on account of his or her disability. It is another thing to be required to attend a childcare facility designed expressly for persons with disabilities. If this were challenged under the Province's human rights legislation, a new set of issues would have to be addressed under the rubric of "bona fide and reasonable justification." The question then bec. .nes not whether an agency has the capacity to provide for the special needs of the child, but whether it can honestly say that those needs cannot be met in the same setting in which typical children's needs are being met. In these circumstances, it is legitimate to ask whether the child's *social*

needs are being met, as well as those connected to his or her disability as such. These issues will be addressed in more detail in our consideration of the application of the *Canadian Charter of Rights and Freedoms*, and also of the *Americans with Disabilities Act*.

It is noteworthy that funding for childcare in British Columbia was administered by the Ministry of Women's Equality. The interconnection of disability and gender equality in the context of childcare was an indication of an attempt to enhance the rights of both groups at the same time.

However, childcare has also recently been moved to a new ministry — the Ministry of Social Development and Economic Security. According to Diane Luscombe of West Coast Childcare Resource Centre, childcare is in "limbo," as it is unclear what the implications of this change are. Some are hopeful that the emphasis will remain on early child development. Others express concern that there will be a return to seeing childcare as a social program, as opposed to a universal program. In terms of the new "Supported Childcare," Luscombe anticipates it will take three to five years before it is fully implemented across the province and can be properly evaluated.

Alberta

Alberta's legislation dealing with childcare makes no specific reference to children with disabilities. In fact, the Province has no written policy regarding day care for children with special needs. Notwithstanding this omission, there has been an "Integrated Day Care Program" since 1982, which provides assistance for children with disabilities to enable them to participate in mainstream day care centres or approved family day homes. This is now called "Supported Childcare" and has a strong philosophy of inclusion. Supported Childcare is available only in licenced settings. In 1995, there were 400 children with special needs, on average, in regulated childcare settings (Childcare Resource and Research Unit, *Childcare in Canada: Provinces and Territories*, 1995. Ontario: University of Toronto, pp. 43, 45).

In April, 1999, the provincial government completed the transfer of responsibility for all children's services to 18 regional authorities, which mirror the regional health authorities. These authorities have a contractual responsibility to continue Supported Childcare, and, in return, the government provides funding based on the special needs of the child and the type of service required. Client families (depending on their income level) are also entitled to a provincial childcare subsidy. Those parents with low incomes whose children do not have disabilities only qualify for the subsidy if their children spend at least 50 hours per month in the childcare program. If a child has a disability, however, the parents may qualify for a subsidy for less than 50 hours per month, provided they meet the income test. Each agency establishes its own criteria to determine which children are eligible for admission to the inclusive program. Those who are perceived to have needs that the agency is not equipped to meet are relegated to Handicapped Children's Services (HCS), which are also now regionalized. HCS remains both a source of funding, and of appeals.[11] They may also be referred to segregated intervention programs, funded by the regions, which aim to prepare children for mainstream education.

Alberta was the last jurisdiction in Canada to include disability as a protected status under its human rights legislation, now known as the *Human Rights, Citizenship and Multiculturalism Act*.[12] Section 3 of the *Act* reads as follows:

> 3 No person shall
>
> (a) deny to any person or class of persons any goods, services, accommodation or facilities that are customarily available to the public, or
>
> (b) discriminate against any person or

> class of persons with respect to any goods, services, accommodation or facilities that are customarily available to the public,
>
> because of the race, religious beliefs, colour, gender, physical disability, mental disability, ancestry, place of origin, marital status, source of income or family status of that person or class of persons or of any other person or class of persons.

While this wording suggests that it would be a clear contravention of the *Act* to exclude any child from a day care program on the basis of the child's disability *or* on the basis of the family being dependent on social assistance, the *Act* may excuse the agency by the operation of s. 11.1, which reads

> 11.1 A contravention of this Act shall be deemed not to have occurred if the person who is alleged to have contravened the Act shows that the alleged contravention was reasonable and justifiable in the circumstances.[13]

Generally, what is "reasonable and justifiable" in human rights cases is determined by the application of an "undue hardship" test. In the context of childcare services, if the behaviour of the child or the magnitude of his or her care needs would be deemed to exceed what the agency could be expected to accommodate within the limitations of its financial or professional resources, then a court could rule that a human rights complaint could not be sustained.

Another test applied by the courts in determining what is "reasonable and justifiable" is whether requiring an agency to admit a particular individual would change the essential nature of the service, making it, for example, no longer a day care service, but a health care service. This is not to say that a childcare agency cannot be required to admit individuals who require any interventions that might normally be thought of as health care services. Administering medications, whether routinely or in emergency situations, has been recognized as a legitimate role which childcare agencies should assume where a child's need for such treatment is manageable without seriously interfering with the essential nature and function of the childcare agency. There will be further discussion of the reasonable justification principles when we examine the impact of the *Canadian Charter of Rights and Freedoms* in the Canadian context below.

Canadian Charter of Rights and Freedoms

All Canadian provincial, territorial and municipal governments, and any agencies to whom any level of government delegates authority over childcare services, are bound by the provisions of the Canadian Charter of Rights and Freedoms, which, since 1982, has been part of the Canadian Constitution. In particular, when considering access to appropriate childcare by children with disabilities, the equality rights enshrined in s. 15 of the *Charter*, are relevant. Section 15(1) of the *Charter* reads as follows:

> Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or *mental or physical disability.*[14]

However, the reality is that parents in Canada, regardless of their socio-economic status or whether or not their children have disabilities, have no legal right to require that childcare services be provided. If such rights arise, it is because governments have entered the childcare field both by subsidizing programs and fees, and by regulating the quality of the care provided. They are consequently obliged by their own human rights laws and by the Constitution to deal in an even-handed way with all who might

wish or need to take advantage of such services.

Since the human rights legislation of that jurisdiction would prohibit discrimination on grounds of disability, then a government or an agency acting on behalf of the government would be discriminating if they refuse to provide the additional funding required in order for the care provider to fully accommodate and support needs that a child with a disability might have. It could also be discriminatory for an agency to require a child to be served by a specialized centre where children with disabilities are not integrated with typical children. This would be discriminatory not only because of the exclusion of the child from contact with his or her peers who do not have disabilities, but also because it might create hardship for the parents who would ordinarily be able to place their children in childcare centres nearer their places of employment or to their homes. If the parent requiring childcare services for a child with a disability were a woman, which is highly likely, and/or where she or he were also currently dependent on social assistance, there could be additional prohibited grounds of discrimination by reason of sex and/or source of income. Human rights legislation has a quasi-constitutional force in Canada, and is binding on private persons as well as on governments.

Ultimately, subs.15 (1) of the *Canadian Charter of Rights and Freedoms* imposes obligations on governments and those acting with the authority of government to ensure equal protection and equal benefit of the law without discrimination based on sex and on mental and physical disability, or on analogous grounds that could include socio-economic status. These are all factors that could come into play with regard to the provision of childcare services.

Although there can be little doubt that many parents of children with disabilities have experienced discrimination with respect to the availability and quality of the childcare services they required in Canada, there does not appear to have been specific litigation on those issues. Contact has been made with legal clinics most likely to have been called upon to represent clients with such complaints, such as ARCH: A Legal Resource Centre for Persons with Disabilities, and Justice for Children and Youth, and to their knowledge no such cases have been decided in this country. Recent movements, discussed above, towards fully inclusive childcare services may be expected to make it even less likely that parents will resort to litigation in the coming years. The case law reviewed here has been with respect to more general disability rights issues, particularly those in which the *Charter of Rights* has been applied.

Case Law

The Supreme Court of Canada originally defined s.15 equality rights in the 1989 case of *Andrews v. Law Society of British Columbia*.[15] The test of whether a law or government action is discriminatory within the meaning of s.15(1) of the *Charter* laid down in that case was whether a distinction has been made on the basis of a prohibited ground that has the effect of withholding a benefit from the person that would not be withheld from other persons, or of imposing a burden or disadvantage on the person that would not be imposed on other persons. If these adverse effects are not experienced, then the distinction that was made does not constitute discrimination, and the *Charter* guarantee of equality has not been violated. Mr. Andrews had been denied the right to seek admission to the bar of British Columbia because he was not a Canadian citizen. Even though citizenship is not listed in s. 15 of the *Charter* as a protected class, the Court held that it is analogous to the designated groups, and therefore comes within the scope of the equality guarantee.

No s.15 cases based on grounds of disability

found their way to the Supreme Court until the case of *Eaton v. Brant County Board of Education in 1996.*[16] In that case, the parents of a young girl with both physical and intellectual disabilities argued that she had a constitutional right to be educated, with appropriate supports, in the same classroom in her neighbourhood school attended by children without disabilities. The school board said that she should be placed in a special segregated class in a more distant school. It was the decision of the Court that being required to be educated in a segregated special class for children with disabilities, on the facts of Emily Eaton's case, was not discriminatory under the *Charter.*

The *Eaton* decision was based on the Court's questionable conclusion that Emily could not benefit by being included in a regular class. The fact that she had been doing so for three years after her parents transferred her to the Roman Catholic Separate School Board was not part of the evidentiary record in the appeal heard by the Supreme Court. The Eatons had been successful in their appeal to the Court of Appeal for Ontario without having to introduce the fresh evidence of Emily's experience in the Separate School system. As respondents in the public Board's subsequent appeal to the Supreme Court of Canada, they were not in a position to seek leave to introduce fresh evidence. Consequently, the only evidence before the Court (apart from that of her parents) pertaining to Emily's capacity to be educated in an integrated classroom, came from witnesses who were employees of the appellant School Board that had been forced to keep her in a regular classroom by a lower Court's injunction.

The Supreme Court's reasons for judgment in the *Eaton* case acknowledged that "integration should be recognized as the norm of general application because of the benefits it generally provides."[17] These benefits, had they been proven in Emily Eaton's particular circumstances, would presumably have been sufficient to establish her equality right, under s.15 of the *Charter,* to take advantage of them. The Court also stressed the requirement that providers of services on behalf of government must take all reasonable measures to accommodate the special needs of persons with disabilities in order to enable them to benefit from those services. However, in Emily Eaton's case, the Court found that the most appropriate accommodation was to place her in the segregated class.

While the Supreme Court recognized in *Eaton* that education provides children with opportunities for both academic and social development, and that there is a long history of exclusion and marginalization of persons with disabilities, the primary focus was on Emily's inability to participate meaningfully in any aspects of the ordinary curriculum in use by all other children in the regular classroom. Had her case been one in which she had been excluded from an ordinary childcare centre, it is quite conceivable that the Court would have found that her social development needs would best be met alongside of children without disabilities.

In 1997 the Supreme Court of Canada handed down another equality rights decision in *Eldridge et al. v. Attorney General of British Columbia,*[18] in which a group of deaf persons complained that they were wrongly denied the services of a sign-language interpreter when they sought the care of a physician under that Province's universal health insurance plan.[19] The Supreme Court found this to be discriminatory within the meaning of s.15 of the *Charter,* and the complainants were granted the right to have an interpreter, provided at government expense, in any situation in which a hearing patient would expect to enjoy full and free communication with his or her health care practitioner.

Justice La Forest, who wrote the reasons for judgment in the *Eldridge* case, acknowledged that the historical context of disability and

inequality called for a broad remedial measure on the part of the Court:

> It is an unfortunate truth that the history of disabled persons in Canada is largely one of exclusion and marginalization. Persons with disabilities have too often been excluded from the labour force, denied access to opportunities for social interaction and advancement, subjected to invidious stereotyping and relegated to institutions. . . . This historical disadvantage has to a great extent been shaped and perpetuated by the notion that disability is an abnormality or flaw. As a result, disabled persons have not generally been afforded the "equal concern, respect and consideration" that s. 15(1) of the *Charter* demands. Instead, they have been subjected to paternalistic attitudes of pity and charity, and their entrance into the social mainstream has been conditional upon their emulation of able-bodied norms.[20]

In the context of day care services required for children with disabilities, these words could hardly have been better chosen to ensure that any attempt to deprive such children of such services by reason of their disability, or indeed to offer segregated care, would constitute discrimination under s.15 of the *Charter.*

The Supreme Court's decision in *Eldridge* also has special relevance to the childcare issue because of the attention paid in Justice La Forest's opinion to the issue of the applicability of the *Charter* to non-governmental agencies to which human services have been delegated. This issue directly relates to the processes underway in Alberta and Ontario leading to privatization of services. The *Charter,* like all constitutional provisions, only applies to state action, not to private entities. However, Justice La Forest wrote in *Eldridge,*

> . . . the *Charter* applies to private entities in so far as they act in furtherance of a specific governmental program or policy. In these circumstances, while it is a private actor who usually implements the program, it is government that retains responsibility for it. . . . Just as governments are not permitted to escape *Charter* scrutiny by entering into commercial contracts or other "private" arrangements, they should not be allowed to evade their constitutional responsibilities by delegating the implementation of their policies and programs to private entities.[21]

Another question that was before the Supreme Court in *Eldridge,* which it was not asked to address in Eaton, is that of the applicability of s.1 "reasonable limits" in cases where the accommodation of the special needs of persons with disabilities may require additional expenditure of public money. Section 1 says,

> The *Canadian Charter of Rights and Freedoms* guarantees the rights and freedoms set out in it subject only to such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society.[22]

The government of British Columbia had argued that the cost of sign language interpretation for all deaf persons in health care settings would constitute such a reasonable limit. Courts are generally reluctant to order governments to spend money that they had not budgeted for. However, in *Eldridge,* Justice La Forest took the position that the relatively small cost of providing interpreter services was not a reasonable limit under s. 1.[23] Should the reasonable limits issue arise in a case involving the additional costs of providing childcare for children with disabilities, where it had been established that a refusal to provide such services on equal terms with services available to children who do not have disabilities, presumably the *Eldridge* precedent would mean that the government responsible for funding the service could not evade its responsibilities because of such costs.

Before leaving our discussion of the implications of the *Charter*, some attention should be paid to subs. 15(2), which is intended to protect affirmative action programs from complaints of discrimination because they provide services exclusively for certain groups. That s. states:

> Subsection (1) does not preclude any law, program or activity that has as its object the amelioration of conditions of disadvantaged individuals or groups including those that are disadvantaged because of race, national or ethnic origin, colour, religion, sex, age or *mental or physical disability.*[24]

It is possible that a childcare provider who segregates children with disabilities from other children would attempt to defend this practice by claiming that the segregated service better serves the interests of children with disabilities than would an integrated service that accepted all children, regardless of disability.

The Court of Appeal for Ontario, in *Lovelace v. Ontario*, has rejected the notion that subs. 15(2) can be used as a defence against allegations of discrimination brought by the very persons the separate program was supposedly intended to benefit:

> We view s.15(2) of the *Charter* as furthering the guarantee of equality in s.15(1), not as providing an exception to it. . . . The purpose of the equality guarantee in s.15(1) is to remedy historical disadvantage, that identical treatment can perpetuate disadvantage and that equality may sometimes require different treatment. Section 15(2) enhances this concept of equality by recognizing that achieving equality may require positive action by government to improve the conditions of historically and socially disadvantaged individuals and groups in Canadian society. We therefore read ss. 15(1) and 15(2) of the Charter together to embrace this one consistent concept of equality. *Treating s. 15(2) as an exception or defence to s. 15(1) is antithetical to this concept.*[25]

The appropriate test for the application of subs.15(2) would seem to be found in its wording. Will a separate program in fact lead to "the amelioration of conditions of disadvantaged individuals" in ways that could not be achieved within an inclusive program? Where disadvantage stems from the social exclusion and isolation of persons with disabilities, the answer would surely be no.

Endnotes

[1] R.S.O. 1990, c. D-2.

[2] *Childcare in Canada*, Note 1 above, p. 28.

[3] R.R.O. 1990, Reg. 262, s. 59.

[4] R.R.O. 1990, Reg. 262, s. 60.

[5] *Childcare in Canada*, Note 1 above, p. 31.

[6] R.S.O. 1990, c. H.19, s. 17 (2); 1994, c. 27, s. 65 (2).

[7] British Columbia, Special Needs Day Care Review Reference Committee, *Supported Child Care*, British Columbia: Minister of Supply and Services, 1993.

[8] RSBC, 1996, c. 26.

[9] *Ibid.*, s. 2 (emphasis added).

[10] *Human Rights Code*, R.S.B.C. 1996, c. 210, s. 8(1).

[11] Perdita Baier, Assistant to the Director, Day Care Programs, Government of Alberta, personal communication, April 13, 1999.

[12] R.S.A., c. H-11.7, 1996.

[13] *Human Rights, Citizenship and Multiculturalism Act*, Note 3 above, s. 11.1.

[14] *Charter*, s. 15(1), (emphasis added).

[15] *Andrews v. Law Society of British Columbia*, [1989] 1 S.C.R. 143.

[16] *Eaton v. Brant County Board of Education*, [1997] 1 S.C.R. 241.

[17] *Ibid.*, para. 68.

[18] *Eldridge v. British Columbia (Attorney General)*, [1997] 3 S.C.R. 624.

[19] *Hospital Insurance Act*, R.S.B.C. 1996, c. 204, and *Medical Protection Act*, R.S.B.C. 1996, c. 286.

[20] *Eldridge*, Note 28, para. 56.

[21] *Ibid.*, para. 42.

[22] *Charter*, Note 23, s. 1.

[23] *Eldridge*, Note 28, para. 94.

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